University of Alberta

Male Caregivers Of Adults with Cognitive Impairment: Perceptions of Formal Support

by

Maureen Greer Coe

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **Male Caregivers of Adults with Cognitive Impairment: Perceptions of Formal Support** submitted by **Maureen Greer Coe** in partial fulfillment of the requirements for the degree of Master of Nursing.

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Date: Sept 4, 1996

DEDICATION

To my parents, **Mary and Jack Morton**, who have been unfailing sources of support to me. My mother has demonstrated throughout her life the meaning of love and caregiving. My father, whose memory I cherish, has instilled in me the value of patience, perseverance, and pursuing further education.

To my husband **John Coe** who has been steadfast in his love, patience, and encouragement and who gave me a sense of balance through his common sense and humour.

ABSTRACT

The purpose of this study was to explore perceptions of formal support of male caregivers of adults with cognitive impairment. Grounded theory methods were employed in the secondary analysis of data from interviews with 24 men and a focus group. The men experienced a 4-stage process of making concessions for care: resisting, giving in, opening the door, and making the match. Personal barriers deterred the caregiver from seeking help and system barriers existed when the caregiver sought help. While engaging formal help, the caregiver redesigned his role and was influenced by enabling or disabling behaviours of formal helpers and system characteristics. Outcomes occurred that influenced the caregiver's further use of formal supports and resulted in satisfaction or dissatisfaction. The findings provide a basis for nursing practice and research.

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Chapter 1

Introduction

The family is the primary provider of care and a valuable continuing resource when a family member experiences cognitive impairment. There are over a quarter of a million elderly people with dementia in Canada and the number of cases will almost triple by the year 2031 (Canadian Study of Health and Aging Working Group, 1994). The public health impact of dementia extends beyond the care recipients to family caregivers, whose well-being may be threatened by the caregiving role (Baumgarten, 1989). Family caregivers of adults with cognitive impairment assume a role that may dramatically impact every aspect of their lives, including their health. Maintaining the well-being of this group is essential and can be accomplished only by thoroughly understanding caregivers' needs and resources.

Support is a significant mediating factor in the caregiver's response to the caregiving situation. Support may be provided informally by other family members and friends or more formally by professionals and paraprofessionals. Support is linked with health and it is the individual's perception of support, rather than the amount of actual support received, that is the best predictor of health (Heller, Swindle, & Dusenbury, 1986; Pallett, 1990; Stewart, 1993; Tilden, 1985). Little is known about caregivers' perceptions of formal support, yet this information is essential for nurses and other health professionals to intervene effectively and

efficiently to meet caregivers' needs.

The response to the caregiving role and the caregivers' use of support may be influenced by gender. The majority of caregivers are female yet males also make a significant contribution to caregiving (Kaye & Applegate, 1990); males constitute 27% to 28.5% of caregivers of noninstitutionalized elderly (Chang & White-Means, 1991; Stone, Cafferata, & Sangl, 1987). The experience of males is underrepresented in both the caregiving (Chappell, 1992) and support (Stewart, 1993) literature. It is therefore important that caregivers' perceptions of formal support be examined and that male and female perceptions be identified.

The study of male caregivers' perceptions of support requires an approach that will reveal the caregiver's perspective and capture the multidimensional experiential aspects of both caregiving and the use of support. For these reasons a qualitative method of inquiry is both suitable and necessary as it permits the examination of the caregiver's experience of support using an emic and holistic approach as well as an inductive, interactive process of inquiry (Morse, 1992).

Relevance for Nursing

This study is important to nursing because health risks are associated with the caregiver role. Support, particularly perceived support, is most closely associated with health but little is known about male caregivers' perceptions of support. The nursing profession represents a significant component of

the social network from which caregivers receive formal support. It is therefore important for nurses to determine how that support is perceived and to use this information to enhance nursing care.

Statement of Problem and Purpose

Caregivers of adults with cognitive impairment constitute a vulnerable group whose well-being may be affected by the role. Gender influences response to the caregiving role and may influence perceptions of support. The majority of research done on caregiving examines women caregivers. It is therefore important that male caregivers' perceptions of formal support be examined. The purpose of this study is to explore the perceptions of formal support of male caregivers of older adults with cognitive impairment.

Research Questions

To fulfill the purpose of the study, the following research questions were examined:

1. What are male caregivers' perceptions of the process of acquiring and using formal support?
2. What is the nature of the relationship between male caregivers and sources of formal support?
3. What is the male caregiver's perception of support in relation to the context of his experience?

Definition of Terms

Caregiving is defined as voluntarily assuming primary responsibility, without renumeration, for the care of an older adult with cognitive impairment. Caregiving may include, but

does not require, the provision of physical care.

Caregivers are male relatives or nonrelatives who identify themselves as having the primary responsibility for care of an older adult with cognitive impairment. They may or may not live with the care recipient.

Social support is the individual's evaluation of the content of key interpersonal relationships (Funch, Marshall, & Gebhardt, 1986).

Formal support is help provided by governmental and non-governmental service agencies and the professionals who work their behalf (Chappell, 1992). It also includes that help which is provided by paraprofessionals such as homemakers.

Social network refers to the structural components of a set of relationships (Chappell, 1992).

Perception is an individual's awareness or understanding.

Chapter 2

Review of the Literature

Families provide the majority of care received by adults with cognitive impariment and the number of family members in caregiving roles will continue to increase as a result of social and demographic trends. Support is an important mediating factor in the caregiver's response to the caregiving situation and in the caregiver's health. Gender influences the caregiver's response to the caregiving role and may influence the use of support.

The literature will be reviewed with respect to caregiving, support, and gender. Findings from relevant qualitative and quantitative studies will be discussed and those studies that involve care recipients with cognitive impairment will be identified where available. The majority of research focuses on female caregivers, a reflection of the prevalence of women in caregiver roles. However, the contribution of male caregivers must not be overlooked. In this review of the literature, the primary focus will be those studies that involve both men and women as well as those studies that focus solely on male caregivers.

Caregiving

Significance of caregiving

The family is the primary provider of care for its members who are ill (Biegel, Sales, & Schulz, 1991) and families provide the majority of care received by adults with cognitive impairment. With social and demographic trends such

as an increasing number and proportion of elderly in the population, emphasis on community-based health care, reduced length of hospital stay, relative reduction in the availability of institutional care and health services, and a reaffirmation of the importance of the family as a primary caregiving group (Biegel et al., 1991), the number of family members in caregiving roles will continue to increase.

Along with the increase in the proportion of elderly in the population, the incidence of dementia, which results in cognitive impairment, will also increase. Dementia affects 8% of persons over 65 year of age and 35% of persons aged 85 and over (Canadian Study of Health and Aging Working Group, 1994). Spouses and adult children, who are most often the caregivers, are significantly challenged by the complex long term care that such impairment necessitates. The vulnerability of the caregiver population in general, and the caregiver population of the cognitively impaired in particular, is well documented (Bunting, 1989; Wilson, 1989).

Although the responsibility for caregiving has been traditionally ascribed to women, men also assume a significant role (Chang & White-Means, 1991; Kaye & Applegate, 1990; Mathew, Mattocks, & Slatt, 1990). Men constitute approximately one third of caregivers seen in clinic settings (Zarit, Todd, & Zarit, 1986). The involvement of men in caregiving is also likely to increase. Increased participation of women in the labour force and high rates of divorce are two trends that reduce the availability of women

to participate in caregiving activities (Dwyer & Coward, 1992). A shift in gender role patterns is evident; for example, more fathers are increasingly becoming more nurturant in the care of their children (Kaye & Applegate, 1990). The increased flexibility in gender roles (Kaye & Applegate, 1990) and the prevalence of Alzheimer's disease among women (Canadian Study of Health and Aging, 1994; Fitting, Rabins, Lucas, & Eastham, 1986) may result in men assuming increased caregiving responsibilities for elderly relatives with dementia.

Caregiving and Cognitive Impairment

Providing care to adults with cognitive impairment presents many challenges. Among the elderly, dementia is a primary cause of cognitive impairment, although impairment may also result from other pathology. In addition to the effects on memory, awareness, and judgement, dementia may result in socially unacceptable behaviour and deterioration in physical function. The changes in the care recipient and the demands of the caregiving role may result in the caregiver becoming socially isolated from others (Pratt, Schmall, Wright, & Cleland, 1985). At the same time, the caregiver must deal with the demands of caregiving, cope with the loss of the relationship with the recipient as it used to be, and witness the steady deterioration caused by the disease. The need for care and supervision escalates as the disease progresses and may result in caregiver fatigue and exhaustion such that the caregiver's own needs are neglected. In addition, economic

hardship may result (Stoller, 1992) and there may be conflicts created within the family (Semple, 1992; Strawbridge & Wallhagen, 1991) and the workplace, if the caregiver is employed (Canadian Aging and Research Network, 1993; McKinnon, 1992; Stone et al., 1987).

Caregiving and its stressors continue even after institutionalization, especially if the caregiver maintains close contact (Dellasega, 1991; Mathew et al., 1990; Pratt et al., 1985; Stephens, Kinney, & Ogrocki, 1991). The caregivers may continue to perceive themselves as primarily responsible for the care received (Stevens, Walsh, & Baldwin, 1993; Willoughby & Keating, 1991; Wilson, 1989). New stressors associated with the caregiving role may replace old ones. As a result of the stressors associated with the role, caregiving may impact upon the health of the caregiver.

Caregiving and Health

Costs and benefits result from the caregiving experience, although greater emphasis in the literature is placed on the negative effects. Burden, burnout, strain, and distress are words frequently used in relation to the experience. Burden, a subjective state reflecting the perceptions of the individual caregiver (Biegel et al., 1991), plays a central role in influencing the impact of the elder's impairment on the caregiver and the family (Poulshock & Deimling, 1984).

The impact on the caregiver is most often described in terms of effects on caregiver mental and physical health. Depression is the most commonly described effect (Drinka,

Smith,& Drinka, 1987; Fitting et al., 1986; Haley, Levine, Brown, Berry, & Hughes, 1987). Effects on physical health are most often identified through self-reports wherein caregivers generally perceive their health to be poor (Chenoweth & Spencer, 1986; Haley et al., 1987a; Stone et al., 1987). Poorer immune response among Alzheimer dementia caregivers than among their matched age peers is also reported (Kiecolt-Glaser, Glaser, Shuttleworth, Dyer, Ogrocki, & Speicher, 1987).

The effect of caring for persons with dementia as compared with other care recipients may be more detrimental. Of the three dimensions of disease severity - cognitive impairment, functional impairment, and behavioural disturbance - there is strongest support for an association between the severity of the patient's behavioural disturbance and caregiver health (Deimling & Bass, 1986; George & Gwyther, 1986; Kiecolt-Glaser et al., 1987) though not all studies (Haley et al., 1987a; Zarit, Reever, & Bach-Peterson, 1980) support this association. The results of studies that examine effects on caregiver health are suggestive of negative health effects but are not conclusive (Schulz, Visintainer, & Williamson, 1990). Recruited subjects may represent those caregivers who are most distressed, thereby resulting in sample selection bias. The sample sizes are small and it is difficult to know how to interpret self-report data. Although it is reasonable to expect that the stress of caregiving may adversely affect health, definitive morbidity effects are

difficult to obtain because other factors may obscure results. Most caregivers are married and married persons are known to have better health (Ross, Mirowsky, & Goldstein, 1990). Illness effects may actually occur after the caregiving role has ended, and the negative effects of caregiving may be counteracted by benefits (Schulz et al., 1990).

The benefits of caregiving are acknowledged but receive relatively little attention. Improvement in the spousal relationship since assuming the caregiving role (Fitting et al., 1986), as well satisfaction (Hooyman, Gonyea, & Montgomery, 1985), pride (Davies, Priddy, & Tinklenberg, 1986), and an increased sense of closeness (Motenko, 1988) are reported positive effects.

Caregiver Relationship and Gender

As already indicated, men contribute significantly as caregivers. In a large national study of caregivers of noninstitutionalized elderly in the United States (Stone et al., 1987), 71.5% of caregivers were female and 28.5% were male. Of the male caregivers, 12.8% were spouses, 8.5% were sons, and 7.2% were other relatives and nonrelatives. In the Alberta Survey (McKinnon, 1992), 30% of the 1277 respondents said they were providing some type of assistance to an elderly relative. Of these respondents, equal percentages of men and women said they were involved in elder care.

Generally the majority of caregivers are women but the gender gap narrows when only spousal caregivers are considered (Pruchno & Resch, 1989). Of all spousal caregivers, more than

one third are male (Stone et al., 1987).

The experience of caregiving spouses may be described with respect to caregiving tasks and the impact on the caregiver. As primary caregivers, spouses handle a broader range of tasks, provide more hours of assistance (Tennstedt, McKinlay, & Sullivan, 1989), are more likely to provide personal care (Stone et al. 1987), and tolerate greater disability for a longer time with fewer resources and at greater personal cost (Hess & Soldo, 1985; Horowitz, 1985a). Spousal caregiving is associated with less role conflict and lower levels of burden (Johnson & Catalano, 1983; Young & Kahana, 1989) although this finding is not supported by all researchers (Cantor, 1983; George & Gwyther, 1986). The prevalence of health problems among spousal caregivers is greater in comparison to their noncaregiving peers (Fuller-Jonap & Haley, 1995; Pruchno & Potashnik, 1989) possibly due to role demands, and in comparison to caregiving sons and daughters (Barnes, Given, & Given, 1992) possibly due to the age of the spousal group.

Male and female spouses differ in their experience of the caregiving role. For example, women experience more stress in the form of depression (Fitting et al., 1986; Pruchno & Resch, 1989), report higher levels of emotional distress (Horowitz, 1985a), and experience greater strain in family relationships and report greater decline in health (Barber & Pasley, 1995). Changes in sex roles in later life may account for these results (Gutmann, 1987); women may resent returning to the

caregiving role and men may become more expressive and nurturant.

The stress of the caregiving role is also experienced by adult children. In the United States, adult children constitute 37% of caregivers of the noninstitutionalized elderly (Stone et al., 1987) with males representing about 1/4 of this number. Although daughters and daughter-in-laws are most frequently the adult-child caregivers, sons also sustain bonds of affection, perform certain gender-defined tasks, and become the responsible relative for elders who have no daughters or none close-by (Brody, 1985).

The caregiving tasks performed by daughters and sons have also been identified. Daughters are more likely than sons to help with household chores and provide personal care (Horowitz 1985b; Kramer & Kipnis, 1995; Stoller, 1990). Sons are more likely to assist with home repairs and maintenance tasks (Stoller, 1990). Similar to these findings, results of the 1992 Alberta Survey indicate that women are more likely than men to provide assistance with house cleaning and meal preparation while men are more likely to provide assistance with finances and yard work (McKinnon, 1992). In contrast to these findings, however, there was no significant difference in emotional care or personal care provided by men and women in the Alberta Survey. Although 75% of the respondents in this survey are under 50 years of age, indicating the likelihood of other than a spousal relationship, the results are interpreted tentatively as the relationship to the care

recipient is not identified.

The impact of the caregiving role differs between adult-child caregivers and spousal caregivers. The adult-child must deal with family responsibilities and employment issues. Elder caregiving combined with employment results in increased stress, work-family conflict, higher absenteeism, and job opportunity costs such as lost promotions and inability to take on additional work projects (Canadian Aging and Research Network, 1993). Caregiving which limits labour force participation also impacts financially upon the caregiver (McKinnon, 1992). In addition, the role reversal associated with the care of an increasingly dependent parent differs from the experience of the spousal caregiver.

Psychological and sociological perspectives have most often been used to explain differences between men and women with respect to caregiving. The psychological perspective posits that caregiving is central to female identity (Graham, 1983) and that women, through their connections to others, are more caring and nurturant than men (Abel, 1986; Gilligan, 1982). Women are more likely to have an ethic of responsibility that focuses on connection between individuals whereas men are more likely to focus on separateness of self from others (Gilligan, 1982). Sociologists assume that socialization into different roles accounts for the differences between men and women. However, not all results of studies of male and female caregivers are readily supported by these explanations. The study of gender is challenging in

that age, kin, characteristics of the caregiver and care receiver, the quality of the relationship prior to the onset of caregiving, and many other factors influence the interactions and make differentiation according to gender difficult (Horowitz, 1992). The experience of male caregivers may also challenge typical stereotypes. Although polarized differences have been identified between men and women, similarities between genders and differences within genders are also identified (Opie, 1994). Male caregivers have also demonstrated what might be considered atypical reactions to the role. They have demonstrated commitment (Harris, 1993; Motenko, 1988), experienced a sense of accomplishment (Harris, 1993), enjoyment, pride (Motenko, 1988), or emotional gratification and satisfaction (Archer & MacLean, 1993; Kaye & Applegate, 1990), and minimized the hardships they experienced (Vinick, 1984).

Summary

Family members provide the majority of care to adults with cognitive impairment and continue in the caregiving role after the care receiver is institutionalized. Men assume the caregiving responsibilities in some families, especially when their wives are affected by Alzheimer's disease. Although the health of all caregivers may be adversely affected by the role, caregivers of spouses with dementia are particularly vulnerable. In some respects the experience of male caregivers differs from their female counterparts and one of these differences may be their use of formal support.

Support

Main Conceptualizations

Social support is a multifaceted term that has been variously defined in the literature. Social support (Sarason, Sarason, & Pierce, 1990) is conceptualized as the individual's connectedness with a social network, the individual's received or reported support, and perceived support or that which the individual believes to be available if needed. Social support refers to the function of relationships and is distinguished from the social network which encompasses the structure of relationships (Cohen & Syme, 1985). Each conceptualization and its measures provide quantifiable information about support, but it is the quality rather than the quantity of support that has a greater impact on outcomes (Antonucci, 1985). In addition, it is one's perception of social support that is most closely related to health (Heller et al., 1986; Stewart, 1993; Tilden, 1985).

> The quality of supports available and whether or not the caregiver perceives them as being supportive are of utmost importance in determining the effectiveness of support resources in mitigating caregiving stress, and enhancing well-being. (Pallett, 1990, p. 55).

There is some variation in the literature as to what is encompassed by social support. Although social support may be described as synonymous with informal support (Chappell, 1992) or that which involves only family, friends, and neighbours, it may also include health care providers (Stewart, 1993). It

is the latter conceptualization which will be adopted for this study. Social support, then, may include both informal and formal sources of support. Formal support is provided by governmental and nongovernmental agencies and the professionals and staff who work on their behalf (Chappell, 1992). Both formal and informal support involve intrapersonal and interpersonal processes which interface at many points.

Supportive social interactions serve different purposes; the interactions may be affirmational, emotional, instrumental, or informational (House & Kahn, 1985). Affirmational social interactions validate one's sense of personal competency while those interactions with an emotional focus enhance one's ability to deal with a situation. The performance of helpful tasks and activities constitute instrumental behaviours whereas those behaviours that impart knowledge have an informational focus. In addition, the helpfulness of the type of support provided may be linked to the source (Dakof & Taylor, 1990). This link between source and type is important in considering the effect of support on health.

Support and Health

The concept of support is integral to health and well-being although the nature of the relationship is complex and uncertain. Social support is hypothesized to influence health in three possible ways: by preventing stress (mediating-effect model), by buffering the effects of stress (buffering model), or by affecting health in ways unrelated to stress (main-

effect model) (Stewart, 1995). In the mediating-effect model, social support acts as an intervening variable to indirectly alter the effect of stress on health outcomes (Quittner, Glueckouf, & Jackson, 1990). In the buffering model, social support protects the individual from the potentially harmful effects of life stress and enhances coping ability (Caplan, 1974; Cassel, 1974; Cobb, 1976). The main-effect model proposes that social support fulfils basic social needs (Thoits, 1982) and enhances social integration which influences health, possibly through the neuroendocrine or the immune system (Cohen & Wills, 1985).

Perceived support (rather than received or reported support or connectedness with a social network) is most closely associated with health (Stewart, 1993; Heller et al., 1986). Perceived support is the generalized appraisal by individuals that they are cared for, valued, have help available in the event of need, and are satisfied with their social relationships (Heller et al., 1986). It is, therefore, not supportive behaviour itself that affects health but how the individual perceives and interprets that behaviour.

Social interactions may have a positive or negative influence upon health. For example, interactions may foster healthy behaviour and health care use such that health is enhanced (Stewart, 1993) whereas stressful social interactions may prolong physical dysfunction (Kaplan & Toshima, 1990) or result in poor emotional health (Schuster, Kessler, & Aseltine, 1990).

Support and Caregiving

The availability of support to caregivers and its effects vary, although most support is provided by family, friends, and neighbours (Chappell, 1992). Sources of formal support may include respite care, support groups, home care services, educational programs, or the provision of care in a long term care facility. Social support has been demonstrated to enhance caregiver outcome (Haley, Levine, Brown, & Bartolucci, 1987; Lindgren, 1993; Poulshock & Deimling, 1984) but not always to the extent expected (Zarit & Toseland, 1989). In addition, the kind of support provided affects caregiver outcome (Reinhard, 1994; Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993; Woods, Yates, & Primomo, 1989) and some forms of support have negative effects (Chappell, 1992; Tilden & Gaylen, 1987). For example, engaging in social interaction for fun was most important in diminshing the burden of caregiving among family members of frail elders (Thompson et al., 1993) while practical advice on managing disruptive behaviour reduced burden among family members of mentally ill persons (Reinhard, 1994). In the event of chronic illness (Woods et al., 1989), instrumental support may be more effective to address the direct effects of the disease whereas emotional and informational support may be most effective to address concerns about the future.

Support, Caregiving, and Gender

Patient and family perceptions of experiencing support from nurses and other health professionals is a relatively

unexplored phenomenon (Gardner & Wheeler, 1987). Little attention has been paid to the social context of support which refers to those ideas, beliefs, and values held by people that influence their use of support. Understanding this context as it relates to caregivers of persons with cognitive impairment, for whom support is so important, is essential for planning effective interventions.

Gender differences exist among caregivers in the use of formal and informal support (Barusch & Spaid 1989; Miller, 1987). For example, women make more use of physicians, support groups, and counselling whereas men make more use of help with home nursing and housework. Male caregivers tend to minimize the extent to which they use formal support (Kaye & Applegate, 1990; Motenko, 1988). Therefore, it is useful to consider gender in relation to perceptions of formal support.

Summary

Support is provided by informal or formal sources and may have positive or negative effects. The quality of support has a greater effect on outcomes than the quantity of support. Perceived support is most closely associated with health, yet little is known about perceptions of support. If both the quality of the support and perceptions of support are important to health outcomes, then both should be examined.

Caregivers constitute a group whose health may be adversely affected by the role and who may benefit from formal support. Gender influences response to the caregiving role and may influence caregivers' use of support. It is therefore

important that caregivers' perceptions of formal support be examined and that male and female perceptions be identified.

Relevant Qualitative Studies

Two groups of qualitative studies are relevant to this literature review. First, qualitative studies that involve both male and female participants and explore various dimensions of providing care to family members with dementia will be reported. Then the studies that involve only male caregivers will be described.

Dimensions of Caregiving - Male and Female Participants

The phases of the process of caregiving were identified in two studies. Wilson (1989) studied 20 family caregivers and identified the phases of taking it on, going through it, and turning it over. During the experience the basic social-psychological problem was described as coping with negative choices. Lindgren (1993) described the experience of 10 caregiving spouses as a fatalisitic career encompassing three stages - encounter, enduring, exit - much like those described by Wilson.

Morgan and Laing (1991) examined the response of 9 spousal caregivers to the diagnosis of Alzheimer's disease. Two groups of caregivers were identified: those who were motivated by love and experienced grief and those who were motivated by responsibility or duty and experienced role strain. The couple's previous relationship determined whether the caregiver's response was associated with grief or role strain.

Two studies focused on the experience of caregivers in making a decision to institutionalize their family member. Willoughby and Keating (1991) identified a five-stage process of gaining and relinquishing control of caregiving: emerging recognition, taking control, losing control, adjusting to the psychiatric institution, and moving on. Dellasega and Mastrian (1995) examined the process and consequences of institutionalizing an elder. In this study the caregivers perceived the decision to be theirs alone and the consequences included emotional turmoil, ambivalence, and role redefinition.

Bowers (1987) conducted 60 interviews with 27 parents and 33 of their offspring to examine intergenerational caregiving. The categories of caregiving that were identified were anticipatory, preventive, supervisory, instrumental, and protective. The presence of these conceptual categories was also supported by Corcoran's (1994) study of management decisions made by 26 caregiving spouses of persons with Alzheimer's disease.

Chesla, Martinson, and Muwaswes (1994) studied the relationships within 30 families who cared for a member with Alzheimer's disease. Three forms of relationships were identified in which continuity and discontinuity were salient features: the relationship with the care recipient was continuous with the relationship as it was prior to the onset of the disease, the relationship was continuous but transformed since the onset of the disease, or the

relationship was radically transformed.

Opie (1994) addressed caring from the perspective of behaviours and emotional attitudes and found a spectrum of behaviours and attitudes that are based on dimensions of love / hate or indifference. The sample of 28 caregivers (including male and female spouses and adult children) demonstrated commitment, obligation, dissociation, or repudiation in their relationships with care recipients. At the heart of commitment was the caregivers' valuing the past and present relationship and believing in their ability to have a positive effect on the care recipient in spite of the level of impairment. This study demonstrated the complexities of gender related research, the behaviours and attitudes that crossed gender boundaries, and the use of qualitative methodology to uncover new dimensions and insights related to gender and caregiving.

The Male Caregiving Experience

There are also six qualitative studies of male caregivers. In 1984 Vinick interviewed 15 widowers who had cared for their wives prior to their deaths to determine the meaning of the caretaking role to the men. The caregivers idealized the memory of their late spouses, expressed reluctance to place their wives in a nursing home, and minimized the hardships they faced. Little information was provided about the care recipients or the process of caregiving.

Motenko (1988) interviewed 6 older men who cared for

their disabled wives. Only one of the wives had a diagnosis of dementia; the others were physically disabled. This study focused on the meaning of spousal care to the caregivers, the meaning of respite care to the caregivers, and the need for and utilization of respite care by male caregivers. To the caregivers, caregiving was a labor of love, a source of pride, a demonstration of commitment, and an opportunity to reciprocate. Formal help with care was accepted only as a temporary means to enable the caregiver to maintain his caregiving role and only from those perceived by the caregivers as trustworthy. The caregivers viewed respite care, which in this study primarily involved the use of home health aids for brief periods of care, as a relief but not a release from responsbility. The caregivers did not use respite for longer terms of relief and they delayed the use of institutional care for their wives. Motenko proposed that the men's role in taking responsibility for the care of their wives was central to their identity and well-being.

Kaye and Applegate (1990) combined reports of a national survey of men engaged in caregiving activities with a national survey of leaders of male support groups and interview data obtained from 30 male caregivers located within a smaller geographical area. An important finding of this study, in which the majority of caregivers were spouses, was their low use of formal services. The formal services included both those delivered in the home such as homemaking, health aid assistance, and nursing assistance, and those available at

congregate sites such as day cares and hospitals. In the caregivers' use of every type of community service, their service needs, measured by a Service Need Index, exceeded their service utilization.

Mathew, Mattocks, and Slatt (1990) explored the personal experiences of 20 men who cared for a relative with dementia. They also compared the experience of those men who cared for a relative at home with those men who had institutionalized their relative. The majority of these men felt a strong sense of responsibility and obligation to provide care. The caregivers experienced similar burden, whether or not the care receiver was institutionalized.

Harris (1993) studied 15 older male caregivers whose wives had Alzheimer's disease. The purpose of this study was to determine from the caregiver's perspective what it was like to be the primary caregiver. Harris identified four types of male caregivers: (a) the worker group who fashioned their caregiving role after their work role, (b) the labor of love group whose devotion to their wives predominated, (c) the sense of duty group whose role emphasized commitment, duty, and responsibility, and (d) the group at the crossroads who were new to caregiving and uncertain about what to do. Harris concluded that gender-sensitive programs are needed for these men, particularly to address their social isolation, and that the group of men whose wives were newly diagnosed should be given priority.

Archer and MacLean (1993) also investigated the meaning

of the caregiving role with 6 male caregivers, two of whom had wives with Alzheimer's disease. These men used outside interests such as hobbies and social relationships in order to cope with their caregiving responsibilities and all received a sense of satisfaction from the caregiver role.

Summary

Various dimensions of providing care to a relative with dementia - phases of the process of caregiving, responses to diagnosis, decision to institutionalize, categories of caregiving, family relationships with the care receiver, behaviours and emotional attitudes toward the care receiver - are explored in these qualitative studies involving male and female caregivers. The six qualitative studies of male caregivers focus primarily on the meaning of the role to the caregiver and indicate that their use of formal supports is low. With the exception of Motenko's (1988) identification of caregivers' feelings about the use of respite service and Mathew et al. (1990) and Vinick's (1984) identification of a reluctance to use institutional care, no information is identified about male caregivers' perceptions of the process of accessing and using formal support. The perceptions of formal support of male caregivers of older adults with cognitive impairment will therefore be examined in this study.

Chapter 3

Method

Grounded theory methods of data analysis were employed in the analysis of data from a previous study. The purpose of the original study was to explore the social support of men who were caring for a person with cognitive impairment. The original analysis involved the perceptions of support and reciprocity in relationships within the social network of family and friends (Neufeld, 1991). The data were analyzed with regard to informal support but not with respect to the caregivers' perceptions of the process of acquiring and using formal support.

Data Collection

In the original study, participants were recruited through public advertisement in adult day care programs, newspapers, and community organizations and through letters of invitation in long term care facilities. Both caregivers of family members residing in a long term care facility and in the caregiver's home were included. The men were eligible to participate in the study if they considered themselves to be the primary caregivers of an older person with cognitive impairment, were able to speak English, resided in the Edmonton area, and had a telephone.

The data were collected primarily through guided interactive interviews (Appendix A) conducted in the participant's home or other location convenient for him. The interviews ranged in length from one to two hours and were

repeated up to three times over the course of 12 to 18 months. A total of 62 interviews were completed. All interviews were audiotaped and transcribed verbatim.

The participants were also invited to take part in a focus group discussion for the purpose of validating preliminary findings from the study and elaborating on their perceptions of their caregiving situation. Seven caregivers participated in the group discussion which was tape-recorded and transcribed.

The interviews and group discussion were supplemented by other documents that provide contextual information. The interviewer maintained field notes of observations and reflections made at the time of the interview. Some participants gave the researcher personal notes made about the caregiving experience. In one case the caregiver provided the notes of a formal investigation about the adequacy of institutional care. Policy information that affected the caregivers' use of services during the period of caregiving was also used.

The data available from the original study was appropriate for use in this study. The focus of the present study, caregivers' perceptions of formal support, is a component of the original study and the data have not yet been analyzed from this perspective. The interview method used in the original study suits the purpose of this study. In addition the availability of the original researcher and the interview tapes, transcripts, and contextual information

enhance the credibility and fitttingness of this data analysis.

Data Analysis

Secondary analysis of the original data was conducted using grounded theory techniques. Secondary analysis has the potential to make efficient and complete use of already collected data, thereby building knowledge systematically in a cost-effective manner and eliminating the need for repeated access to the participants (McArt & McDougal, 1985; Sieber, 1991; Thorne, 1994). This is particularly important for male caregivers who are known to find it difficult to disclose their feelings (Davies et al., 1986). Grounded theory analysis techniques were used to uncover the meaning of the caregivers' experiences with respect to formal support. Grounded theory techniques are appropriate in secondary analysis in that an inductive process of inquiry may be used, the data may be conceptually related and interpreted, and the theory may be validated against the data. The use of secondary analysis, however, precludes the use of theoretical sampling, asking questions of the participants during data analysis, or validating the process identified with participants. A related strength of the original data collection was the review of the content of each interview prior to subsequent interviews. In subsequent interviews, questions were asked to clarify and expand upon the participant's prior dialogue as well as to seek responses in relation to ideas presented by other participants. Despite

these limitations, the use of grounded theory techniques with secondary analysis facilitates further theoretical development.

Data analysis was done using the tape recordings, transcribed interviews, focus group transcript, demographic information, and notes provided by the caregivers. The non-numerical unstructured data indexing searching and theorizing (NUD*IST) computer program (Qualitative Solutions and Research Pty Ltd, 1995) was used to facilitate the coding, memoing, filing, reporting, searching, and retrieval of the data as well as theorizing. Using this program, text pertaining to the same concept was coded and organized to form a conceptual tree and each category was depicted as a node of the tree. The program facilitated examination of relationships between the categories and subcategories. Off-line documents like the caregiver notes were also used in analysis with the NUD*IST program.

The use of coding and memoing procedures (Corbin, 1986; Strauss & Corbin, 1990) with the transcribed interviews formed the primary basis for the analysis. Preliminary categories were identified by reading all of the interviews and listening to some of the tapes. All interviews with one caregiver were reviewed prior to reviewing interviews with other caregivers. As the line-by-line analysis of each interview proceeded, new categories emerged and some categories were combined. As the themes evolved, interviews were recoded to ensure completeness and consistency. The initial coding of the data was largely a

restatement of what was occurring in the caregiver's experience. As analysis progressed, coding became more conceptual. Similarities and differences between caregivers' experiences were identified, and relationships between categories were explored.

Memos were used to document ideas about the data and the theoretical relationships between codes as they occurred to the researcher. Memoing facilitated the identification of patterns, differences, and relationships among the data. All thoughts, speculations, questions, and decisions were documented as they occurred; these memos prompted further exploration of relationships between themes and were incorporated in the analysis.

The use of diagramming (Corbin, 1986; Strauss & Corbin, 1990) also facilitated the discovery of themes and the links between them. The experience of each caregiver was temporally mapped and the meaning attached by the caregiver to each step of the process was named and defined. As names and definitions evolved, each caregiver's experience was reviewed to ensure that the definitions continued to reflect the caregiver's experience. All variations in the process were documented; some variations became patterns that were subsequently incorporated into the diagram and others were identified as being different from the majority. Negative cases prompted further questions and were also incorporated in the analysis. As the parts of the process were conceptually identified and defined, a storyline (Corbin, 1986; Stauss &

Corbin, 1990) was developed to identify the central phenomenon experienced by the caregivers.

Once the analysis of the individual interviews was completed, the transcript of the focus group, in which 7 of the original caregivers participated, was reviewed. The purpose of the focus group was to provide an opportunity to further understand the meaning and nature of support within the caregiving experience and to clarify preliminary research findings with the caregivers.

Meaning was also uncovered by the use of matrices, associations, and explanations. The questions and potential relationships that occurred to the researcher during analysis were examined using the operators for index system searching in the NUD*IST program.

The data from the individual transcripts and the focus group were reviewed until no new categories or relationships were found. At different times, the process of analysis was reviewed with the thesis supervisor to ensure completeness, consistency, and truthfulness.

Trustworthiness

In qualitative methods of inquiry, there are four aspects of trustworthiness: credibility, fittingness, auditability, and neutrality (Guba & Lincoln, 1981). In this study credibility was enhanced by results being confirmed with participants through subsequent interviews, validating results with participants in a focus group discussion, analysis checks by the thesis supervisor, and by documentation of the thoughts

and feelings of the researcher to reveal biases or preconceptions.

Fittingness is achieved when findings are well grounded in the life experiences of the participants and represent the data with both typical and atypical elements (Sandelowski, 1986). In this study fittingness was strengthened by representing the experiences of all participants in the findings and recognizing the limitations of a volunteer sample.

Auditability involves thorough documentation throughout the study such that an audit trail can be traced by another investigator (Sandelowski, 1986). In this study, the use of the NUD*IST program facilitated systematic and accurate documentation of contextual data, methodological decisions, and analytic processes. Consistency was achieved by coding checks with the thesis supervisor who is familiar with the data. Records of all research material are retained for audit purposes.

Neutrality is measured by the confirmability of the research findings. In this study neutrality was enhanced by measures already described to achieve credibility, fittingness, and auditability as well as acknowledgement of researcher biases in documentation.

Ethical Considerations

Ethical clearance for the original study was obtained and ethical approval was obtained separately for this study from the University of Alberta Joint Ethics Review Committee.

The original consent of participants (Appendix B) allowed for subsequent secondary analysis of the data. This is evident in the consent form which indicates that the information provided by the participants may be used for additional analysis in conjunction with the original investigator, provided ethical approval is obtained. In addition to the rights of the participants, secondary analysis requires that the rights of the original investigator and the rights of the secondary researcher be protected (Sieber, 1991). This protection was accomplished through a written contract which addresses issues such as data ownership, publication rights, and participant confidentiality and anonymity.

Chapter 4

Findings

The analysis of the caregiver and focus group interviews resulted in the identification of (a) the caregivers' views of the process of acquiring and using formal support, (b) the nature of relationships that occurred between caregivers and sources of formal support, and (c) the caregiver's perception of support in relation to the context of his experience. Many of the responses of the caregivers pertained to both informal and formal support. The presentation of these findings is from the perspective of the caregivers' use of formal support. Where possible, distinctions made by the caregivers about formal and informal support will be identified. Initially the sample of men will be described; then a description of the process they experienced in acquiring and using formal support will be given. Throughout the description of the process, variations in the caregivers' experiences associated with the context of their experiences will be described. Subsequently, the meaning of the caregiving role and the meaning of support to the caregivers will be described.

Sample

The sample consisted of 24 men who met the eligibility criteria. The caregivers' ages ranged from 33 to 87 years with 20 of the caregivers being over 60 years of age. Their education ranged from less than grade 12 to university graduation. The annual income level of caregivers ranged from less than $20,000 to more than $40,000 and they primarily

represented the middle class with a range of Blishen scores from 26.36 to 110.32 (Blishen, Carrol, & Moore, 1987). All but 5 of the caregivers were retired. The majority of the caregivers were caring for their wives (n=17). The relationship of the other caregivers varied: son (n=3), son-in-law (n=1), brother (n=1), grandson (n=1), and friend (n=1). The length of time in the caregiving role ranged from less than 2 years to greater than 11 years. Of the caregivers, 9 were known to have personal health problems. Only the youngest of the caregivers had other caregiving responsibilities which involved his own children.

At the time of the first interview, 10 of the care receivers resided in the caregiver's home and 14 were receiving institutional care. During the course of the interviews, the residence of 6 care receivers changed from home to institution. All care receivers had some degree of cognitive impairment as a result of Alzheimer's disease (n=17) or vascular dementia (n=5); in 2 cases the diagnosis was not disclosed. The degree of orientation of the care receivers varied; 15 recipients recognized the caregiver at some level, 4 recipients did not recognize the caregiver at all, 3 recipients lost ability to recognize the caregiver during the course of the interviews, and the recognition ability of 3 care receivers was not known. The length of time in institutional care varied from less than 2 years to more than 11 years. In two situations the care receiver died during the course of the interviews.

The Process - Making Concessions for Care

Analysis revealed that the central phenomenon experienced by the caregivers in relation to formal support was making concessions for care. This means that the caregivers yielded reluctantly to the involvement of formal assistance with care. The caregiver made concessions throughout his caregiving career in order to meet his own needs and the needs of his care recipient. There were four phases in the process: resisting, giving in, opening the door, and making the match (Figure 1, p. 97).

Resisting

This phase began with the experience of diagnosis. Some caregivers experienced great difficulty in obtaining a diagnosis when cognitive impairment and behavioural changes occurred; for others the process of obtaining a diagnosis was straightforward. The contact with physicians to obtain a diagnosis or medical treatment was distinct from the use of formal help to assist with providing care. During and following diagnosis, the caregiver resisted the use of formal help with care. Values, beliefs, and characteristics held by the caregiver prevented him from seeking help with care.

Difficulty asking for help. Some caregivers had difficulty asking for formal and informal help and some considered asking for help to be a last resort. Of the 17 caregivers who discussed their feelings about asking for help, 13 of these caregivers indicated a difficulty. The most common reasons for difficulty included the desire to maintain

independence, a sense of personal responsibility for caregiving, and pride. The behaviours of several caregivers demonstrated their independent nature and many others described themselves as independent.

> I'm a very independent guy, I always have been all my life, really and ah as far as asking for help it's got to be quite a bit for me to ask really. I'm just made that way I guess.
>
> If it's got to get done I"ll just do it myself. I don't go around looking for help.

The desire to be independent was often coupled with a sense of personal responsibility.

> I always figure that was my responsibility, nobody else's.
>
> So that's been part of my trouble is ah, probably being too independent and ah, not going to bother anybody else because that's my responsibility and ah, ... she was my wife and my job was to look after her.

Pride also caused some caregivers to resist the use of formal and informal help. One caregiver described it as having to "put your pride in your pocket". Others talked about difficulty admitting to the need for help, feeling it was a dishonour to the family to ask for help from a social services agency, feeling embarrassed about the diagnosis of Alzheimer's disease, and being taught to value family privacy.

> we have been brought up to keep things within the home ... what goes on between dad and mom is nobody's business but our own.

In addition to valuing independence, responsibility, and pride some caregivers referred to their inexperience with asking for help. They had never been in a position to need to ask for help. Other caregivers indicated that through the

caregiving experience they had learned to ask for help. In reflecting upon their experiences, some caregivers recommended other caregivers seek help earlier.

Other caregivers found it difficult to ask for help due to a feeling of obligation to do something in return. It is unclear whether a sense of obligation applied to both informal and formal help. However, some caregivers found it easier to use professional help than help from friends or to hire help rather than use informal help, even if it was available. Perhaps financial renumeration alleviated a sense of obligation to do something in return.

No difficulty asking for help. Not all caregivers indicated difficulty asking for help. Four caregivers indicated they had no difficulty asking for help. In spite of *stating* they had no difficulty asking for help, 3 of these caregivers resisted the use of formal assistance to a degree.

> it's hard to help people ... because maybe they're as stubborn as I was and think you can handle it yourself.
>
> I thought I can carry on but it came to the point where it was impossible.

The third caregiver did not use any formal help at all.

No resisting. One caregiver was explicit in not resisting the use of formal help with care. He had learned from his experience with an alcoholics anonymous group of the need to help and be helped by others. He readily sought professional help when difficulties arose between he and his wife, though he was not aware that the problems they experienced were due to her Alzheimer's disease. Regarding

asking for help and the use of formal support he said

> anybody that turns around and insinuates that [asking for help is a last resort] is ah pride go[oes] before a fall, ah you don't want to admit that you have to have some outside help to attend to a problem within the home ... my God that's what they're out there for, that's why they're on that end of the phone line ... I think the only reason I'm capable of doing it [reaching out and sharing with somebody else] is as a result of my being in the fellowship [alcoholics anonymous group].

Giving In

In the second phase, giving in, the caregiver conceded to the need for formal help with care. This phase involved a critical experience, breaking personal barriers that prevented the caregiver from seeking help, and caregiver acknowledgement of the need for formal help.

Critical experience. The critical experience was a specific event or a series of behaviours that caused the caregiving demands to exceed the caregiver's emotional or physical ability and precipitated acknowledgement by the caregiver that he needed formal help with care. The following quotes are examples of critical experiences.

Specific event:

> I woke up one time and he was in my room with a screwdriver and just hovering above my face with a screwdriver as well. I don't know if he would have hurt me but it was this ... very unpredictable, that kind of brought it to a, I took him to see [the doctor] and that same day he was taken over to [institution].

Series of behaviours:

> you know, [care recipient] really wasn't a problem other than I found her wandering at night and then that started to bother me because you know we have a thumb latch on the inside of the door lock and she's used to turning it ... yes, so I actually did find her at three in the morning in her panties and bra going down the corridor

> and I nearly flipped ... So I brought her back in and put her to bed and she didn't know what it was all about this door lock ... but, even so, I found that I just, I just wasn't getting sleep because I never knew if she going to turn the stove on or if she was going to open a window and climb out. I just wasn't sure any more after that so I wasn't getting any sleep.

Breaking personal help seeking barriers / acknowledging the need for help. In most cases the caregivers did not identify how they overcame those barriers that prevented them from seeking formal help. One caregiver, however, who found it unacceptable to ask for formal help from social services, described how he handled the situation:

> I suppose now we've had medicare long enough that we're getting used to socialized medicine type of thing from the medicare system. And we don't have the stigma attached there any more to seeking help. And that's, was my approach was through the doctor because I was getting to the end of my rope.

The caregivers resisted the use of formal support until there was no alternative.

> I got to the point where I just said to her doctor, look I need some help. I can't keep this up.
>
> but now I realize that ah, you know there's no way that I can do it on my own.

In retrospect another caregiver provided advice for other caregivers:

> if I was really talking to someone now I would say well go hit people for help and ah don't wait around until you're totally frazzled.

Opening the door

Once the caregiver acknowledged his need for formal help he progressed to the next phase, opening the door. In this phase the caregiver accessed the system for formal help with

care. The caregiver sought help, met with a professional for the purpose of obtaining help with care, and developed an awareness of the care options. In the process of seeking help, he sometimes needed to overcome system barriers.

Seeking help. Seeking help is the process of looking for formal help with care and was usually initiated by the caregiver.

> There is help there if you just go after it. The help doesn't find you. You have to go after the help.

> I think if you want to get support I think you've got to ask for it .... You have got to take the initiative yourself.

In other situations formal help was accessed when the critical experience resulted in hospitalization.

Breaking system barriers. The caregiver sometimes needed to overcome system obstacles in obtaining initial access to formal care resources. The first obstacle was lack of information and not knowing where to go for help.

> The average individual is not aware of what's out there until he gets involved in it and starts getting some of the feedback. But to start with he hasn't got a clue where to start.

> we've sort of been stumbling along and doing all this and stumbling our way through it, finding out how to do it.

Once the caregiver knew where to go for formal help, he sometimes encountered other system obstacles. For example, there may be policies which limit the assistance that can be provided. One caregiver referred to his experience as "breaking the ice" as his wife's age limited their eligibility for formal help.

> I tried so many places and they said oh no she's not 65 we can't ... [do] anything for her.

Other caregivers described the application process and difficulties securing formal help.

> Yeah, the application process is kind of gruelling.

> the nurse from the day hospital ... thought we'd get started before Christmas. Well we didn't, it was January before they started her in over there. So I had another three months all on my own.

> all this time I was looking after her at home and also trying to get her into a care home and it seemed like, as though, there was never a place for her to go.

Accessing a link for formal help / developing awareness of options. The primary role of this formal link was to assist the caregiver to obtain help with care. This formal source helped the caregiver to learn about the resources available to assist with caregiving.

> I found that once we got the contact with the home care people and then they were very good about saying alright, this is central placement ah we'll, or we'll refer to this program or that program.

> Yeah, well as things sort of deteriorated and I started to cast about and through Alzheimer's [Society] I became aware of some of these community resources.

> But eventually ah they assigned a social worker to us and she was very helpful and ah was able to give us the names of different agencies such as Family Services, the YWC Family Services and the city, the city have a program, Social Services program.

This formal source helped the caregiver to learn about the resources available, and in some cases, facilitated access to care.

Making the Match

With assistance the caregiver matched services from the

formal system with his needs and the needs of his care recipient. There were two aspects to making this match: engaging formal help and redesigning the caregiver role.

Engaging formal help. The process of engaging formal help was ongoing and circular. The caregiver acknowledged his own needs and those of the care receiver, selected from among the formal options available to help with caregiving, used the option, and evaluated the effectiveness of the formal help. The caregiver continued to acknowledge needs as they occurred and to select or decline other care options.

> I think that was a good part of the difficulty with that program, not that there was something wrong with the program, but we had mismatched the patient and the program ... having found that it was a mismatch, ah I got in assistance in finding a better matchup.

The decision to use institutional care was one with which many of the caregivers struggled. The caregivers resisted using institutional care for as long as possible.

> I had her on a waiting list to go into the [nursing home] but ah the time came to it and I couldn't find it in my heart put her in there.

> I wouldn't want to put her in there as long as I can look after her. As long as I can do it I'm going to do it for her.

As with the initial acknowledgement of the need for formal help, the acknowledgement of the need for institutional care was preceded by a critical experience. The caregiving demands exceeded the caregiver's emotional or physical ability, even if community resources were used.

In selecting the option of institutional care the caregiver went through the process of 'convincing yourself'

and 'giving over'. 'Convincing yourself' involved deciding that insitutional care was best and sometimes continued long after the care receiver was institutionalized.

> I'll keep telling myself well look they're looking after her better than what you can and convincing myself of that and I think it will work out.

'Giving over' was the actual act of relinquishing care to the institution.

> I just don't feel guilty cause I really had decided there was nothing more I could do. I just had, as sad as it was, I just couldn't do any more myself.

In three situations the caregiver opted for institutional care as a first match in engaging formal support. In two of these cases the care receivers' behaviours made it unsafe to continue to live at home. In the third situation, the care receiver needed total care. In the first two situations the processes of 'giving in' and 'giving over' occurred close together. In the third situation, the caregiver was ready to relinquish care but long term placement did not become available for another 2 1/2 years. During that time, the caregiver hired help with care.

Redesigning the caregiver role. Redesigning the caregiver role involved making changes in the role in conjunction with the use of formal help. These changes included how the caregiver provided care, used his expertise with formal helpers, and expanded the role to benefit others.

The caregivers were involved in a variety of caregiving activities but most focused on feeding, walking, and outings. The majority of visits were planned around mealtimes to assist

with feeding. Many caregivers incorporated walking into the visit; if the care receiver was unable to walk, a wheelchair or recliner was used. Caregivers planned such regular outings as a drive or visit home. Other activities focused on providing stimulation: reading the newspaper aloud, playing music, or taking the care receiver to be with others.

> I try to get her to go down to the dining room every evening ... because I think it's good for her to see other people.

Some caregivers made special efforts to maintain a personal focus through activities such as the celebration of birthdays or anniversaries and the provision of favourite foods or plants.

A few caregivers were not as involved in the caregiving role.

> she sleeps most of the time now ... she's got a good place to stay ... I saw her and that's enough.

This caregiver was not as involved in direct care activities but continued his daily visits.

The frequency and duration of contact between the caregiver and care receiver also varied. Of the 16 caregivers who identified the frequency of their visits, 10 caregivers visited daily and the others visited two to five days each week. Some caregivers also scheduled their visits with others to ensure the care receiver was visited every day. The average length of the visit for four of the caregivers ranged from 4 1/2 to 8 hours while three other caregiver visits lasted from 3/4 to 1 1/2 hours. The visit duration of the

remaining caregivers was not disclosed but the activities they described suggested at least a 3/4 hour visit.

While some caregivers continued in the same pattern of visiting, the frequency and duration of visits by others was reduced over time.

> I spent everyday at the hospital until I run myself ragged and they kept telling me but of course I wouldn't listen. Now I tell other people.

> I ah put in less time ... until I came to a point where ah I go everyday for about an hour and a half.

One caregiver's pattern of visiting was opposite to the rest in that he initially visited less frequently.

> I stayed away for the first week ... so she'd get settled in there and then after that I've been sort of going over in the afternoon and ah usually staying until [the evening meal].

Although the pattern of visiting sometimes changed over time, the caregiver often continued to feel responsible for care. Other caregivers more readily relinquished the responsibility for care.

> to her I still feel the same way. I have to be there and I have to do my thing. I'm responsible.

> I'm not about to say well she's in there and I can now forget about her, I've taken care of her and it's up to somebody else to worry about it. I still feel an obligation to go over and visit her, to take her out for her drive, and what have you.

> I find that I'm still tiring myself by going there, and I still have sleepness nights and worry about what's happening and ah, it's hard personally.

One of the caregivers was particularly creative during visits to help his children feel more comfortable in their mother's presence and to attend to his wife's needs at the same time.

> lately the boys come up, we'll go up to the hospital and I'll take the crib board and we'll play crib and put [care recipient] between us and we kind of include her in our conversation even though she never says anything, of course ... and this way it seems to be working a little better ... [my son is more comfortable if] he's got something to do and talk about.

Another theme was the caregivers' need or desire to provide care due to staff shortage.

> if they're busy, which they are a lot of the time... I put her in bed and ... snuggle her down for a sleep cause I can't see her sitting there waiting for a half an hour for somebody to come if I can do it myself.

> with the nurses, the tight schedule that they have I don't bother them too much. If she has to go to the bathroom I take her myself.

> I still go to the hospital and take an awful lot of work off the nurses ... I still feel I have to do it to help her.

Another theme was the caregiver's sensitivity to the boundary between his role and the role of formal helpers. The caregiver was cautious not to overstep what he perceived to be the domain of the formal helpers, yet still retain his involvement in care. In the process of managing this tension, the caregivers established rapport with formal helpers, aimed to reduce the workload of formal helpers, and praised the formal helpers for their care efforts. At the same time some caregivers recognized the value of their own experience and taught the formal helpers the value of their expertise.

The second aspect of redesigning the caregiver role was the use of caregiver knowledge. The caregivers acknowledged and used their intimate knowledge of and experience with the care receiver.

> I don't know anyone who knows my wife's condition or ah any little idiosyncrasy that she has better than myself because we've been married 47 years, and ah the doctor who sees her once a month for 5 minutes and is out the door, knows very little about her.
>
> He's got four prescription drugs but we know what they're for and we stay on top of it all the time. We made it our knowledge and we questioned it due to the fact that we're with him so much and see the different reactions in him.

Through his experience the caregiver was perceptive of the situation of others as well. One caregiver described his interaction with a patient who was trying to eat:

> her vision had gone to the left which happened to my wife for a while as well and ah they sat her at the table with her bowl of soup and her spoon and she kept on hitting the table and that, because the bowl was here and she couldn't see it and no one was doing anything about it, so I got up and walked over and I slid the bowl in front of her and the next thing you know she ate the whole thing.

The third aspect of redesigning the caregiver role was expanding the role, using the experience to benefit others. Ten of the caregivers described how they used the experience to benefit others. The caregivers used a variety of metaphors to describe their ability to relate to others who shared the experience: "same boat", "same shoes", "I've kind of been down the road ... I can give some good direction." They provided support to other caregivers through informal meetings in care facilities, organized support groups, and the Alzheimer's Society.

> and I see these new patients come in. I see their families coming in and I do not hesitate to go up, shake hands with them, introduce myself, and put an arm around them and tell them I know where they're coming from and how they're feeling.

> And a lot of people come there all upset and you can probably help them a little bit by telling them you know the ways things are ... you've learned over the years.

Some caregivers also participated by representing caregivers as consumers of health care on committees, sharing their written experiences with others, and participating in the education of the public about Alzheimer's disease. They also demonstrated a sensitivity to the needs of other patients and described how they helped other patients while visiting.

> I try to visit as many of the patients as I can and say hello and ah give them a hand shake or whatever to let them know that there's somebody that's visiting.

> sometimes some of the other people are eating and they can't reach their second course and I help them with that.

Not all caregivers participated in an expanded role but with few exceptions, caregivers indicated that they were motivated to participate in this study to benefit others.

Conflict. In the process of making the match, episodes of conflict were present in seven caregivers' relationships with sources of formal support. The conflict primarily occurred with the staff in care facilities but also occurred with formal helpers in the community. The primary focus of the conflict was the caregiver's concern about the well-being of the care receiver and the care provided. For example, one caregiver observed that the care receiver's health was deteriorating and that his physical care was not adequate. Another caregiver had to convince the nursing staff that his wife was dehydrated. A related source of conflict was the caregiver's concern about the appropriateness of the care

facility to meet the care receiver's needs. Placement in a mental health facility resulted in conflict when the caregiver found the staff to be unprepared to handle the behaviour of the care recipient. In another situation, conflict occurred when a decision was made without conferrring with the family to place the recipient in a mental health facility rather than a nursing home. In a third situtation the caregiver relinquished care to a facility but subsequently had to retrieve his wife from the facility because they did not know she was incontinent and were not equipped to meet her needs.

There were a few instances where the conflict was not related directly to the caregiver's concern about the care. One caregiver found the nursing staff initially resented his involvement in the care of his wife. "Some of the nurses resented me doing things, I was doing their job." In another situation, conflict between the nursing team leader and the caregiver erupted when the caregiver was smoking in a designated nonsmoking area. He had previously been given permission by other staff members to smoke there.

The consequences of the conflict varied. The result was often caregiver anger and frustration. In two instances the conflict resulted in the caregiver having to "fight" with formal helpers.

> We fought with them too long and we're not going to quit now ... not before we have our say.

In some instances the conflict resulted in solving a problem or inititiating a change in policy. For example, the

admission criteria for one facility was re-examined. In a few situations harmonious interactions with formal helpers also resulted.

Enabling and Disabling Factors

Throughout the process of using formal help, the caregiver was influenced by both enabling and disabling behaviours of formal helpers and characteristics of the formal system. The enabling behaviours and system characteristics gave the caregiver power, skill, or resources whereas the disabling behaviours and system characteristics did the reverse. The caregiver felt satisfaction when he was enabled and dissatisfaction when he was influenced by disabling factors. The caregivers described the enabling factors in terms of the behaviours of formal helpers and the disabling factors as both behaviours of formal helpers and characteristics of the formal system.

Enabling behaviours. The enabling behaviours directly assisted the caregiver to deal with the caregiving situation or assisted in enhancing the well-being of the care recipient, thereby indirectly aiding the caregiver. These behaviours included comforting the caregiver, demonstrating a caring attitude, addressing problems, affirming the caregiver's role, providing assistance with caregiving, and providing information.

The caregiver was comforted by formal helpers listening to him, talking to him, encouraging his expression of feelings, and giving him an opportunity to relate to others

who shared the same experience.

> there's one social worker, she's extremely good with me and we go out every couple of weeks for lunch ... we can sit and talk about anything to each other and that's been most helpful.
>
> I have every Tuesday ... the chaplin closes her door and then we start, and the tears flow like wine ... this is the only place I can really relieve my tension.
>
> The support group ... for caregivers is another exercise that I've gone through ... I think that, although I got support from people from there, I think I also gave support ... I really did feel quite good about that.

The caregiver found that a caring attitude of formal helpers was helpful. This attitude was demonstrated by showing concern and respect for the caregiver/recipient and demonstrating understanding of the situation.

> [the doctor] says I can't do an awful lot for [care recipient] but I can for you. I want you to come back in 6 weeks. He's great, he's a wonderful person ... one of the few health professionals that have ever phoned me about anything.
>
> If I miss a day I feel so bloody guilty about it and I ... phone the nursing station and ask how [care recipient is doing] ... I feel bad about having to phone ... but that isn't the reaction I get from them. Phone any time, ... [we] know how you're, what you're going through.

The caregiver also found it helpful when formal helpers provided an opportunity to discuss the care recipient and responded to problems that were perceived by the caregiver.

> we have the monthly sessions there ... they ... will read out the status of what [the recipient has] gone through ... since the last meeting ... and they'll discuss it with ya ... well with that kind of support background you know ... it's not just a case you put her in a room and that's it.
>
> The administrator of the hospital, I went to her the other day and it was almost like we were old friends when I talked to her and made a request. Within four days the request was followed through and ah I was extremely happy

with the results.

Affirming the caregiver's role involved encouraging the caregiver in his role through acknowledgement and praise, accepting his involvement in care, and showing respect for his expertise.

> [the doctor] comes to see her once a month and ah I'm often there at the time he comes, and we sit down and discuss the whole thing and work it out, so it's really a great improvement.

> some of the nurses over there ask me to talk to ah a lady who was having trouble with adjusting ... so they asked me ... to get in touch with her and I've had a couple of times where we just sat ... I take her to ah the ah Alzheimer's meetings ... I mean I felt more energy by the fact that they would ah ask me to go and help her ... I felt that maybe I'd made some progress myself.

The caregivers also perceived providing relief from care to be helpful. Relief included rescuing the caregiver when he could no longer cope, recommending care options, arranging for respite services, and assisiting with decision-making about care and placement.

> a homemaker was supplied to us in due course ... other services were the bathroom fixtures to steady her getting in and out of the bath ... the counsellor visitation once a week ... these people came in and were a tower of strength to us.

> that was the first time we ever used it [respite], so it was with quite some trepidation that I left her in the care of others for the very first time ... I can't speak highly enough of how well they looked after her ... made me feel really good.

> I came home and thought it over and then I discussed it with the social worker and the doctor and we decided it's the only safe place, she's got to go into those locked wards where she can't let herself out and get away. So I said alright we'll put her in there.

The caregiver also found it helpful when formal helpers

demonstrated concern and applied their knowledge to the care of the recipient. This was exemplified in one situation where the care recipient was losing weight due to difficulty swallowing:

> everything in her diet now is minced and they don't let her feed herself. One of the girls feeds her and there's specific instructions. She gets a mouthful of food and when she's swallowed that they make her dry swallow twice more and then they check to make sure there's nothing left in the mouth before the next spoonful ... [her weight is] running around ... that means she's stable. It's good.

The caregiver also perceived that information about specific topics or resources was helpful.

Disabling behaviours / system characteristics. The caregivers also identified behaviours and system characteristics that were disabling. Many of these behaviours and characteristics were the reciprocal of those that were enabling. Some caregivers first encountered disabling factors as barriers in accessing formal help. The disabling factors either interfered with the caregiving role or with meeting the recipient's needs. Those that primarily interfered with the caregiver's role involved inadequate communication, lack of involvement in decision-making, detrimental advice, lack of understanding, lack of coordination, limited choice, and lack of involvement of the caregiver.

Inadequate communication occurred within and between community agencies and care facilities, between formal helpers and between formal helpers and the caregiver.

> And I can't talk to doctors because they just have 15 minutes or if you're lucky they give you 1/2 an hour ...

> I can't even remember the numbers of things that I want to talk about.

Lack of involvement of the caregiver in decision-making also caused a problem.

> we get into scraps ... mainly because they do things and they don't stop to think what effect it's going to have on anybody but themselves ... who's making all these decisions that all of a sudden we're encouraged to do one thing and they tell us they're going to do another thing. What's going on here?

The caregivers also identified when they perceived professional advice to be detrimental, when there was a lack of understanding of the situation, or when an uncaring attitude was displayed.

> I don't think I got very good advice at the time or encouragement to ah deal with ... [diagnosis of Alzheimer's disease] to bring it right out ... I think if I'd have dealt with [the diagnosis] up front right from the start I think I would have been able to deal with friends more easily and ah, maybe we could have talked about it in her presence a bit you know.

> there is a weakness in dealing I think with diseases like Alzheimer's ... your professional isn't that close ... doctors prescibe everything at arm's length and tell you to come back in a couple of days and ... you just go down to zero waiting for something to happen.

> when you've got to take him into the Emergency ward you wait and wait and wait. They don't consider that you've got an elderly person on your hands and that you've got to try and do something with ... you're just one of them numbers.

Three caregivers identified a lack of coordination in the care placement process as problematic. One caregiver indicated that the biggest need was to streamline this process.

> we went from [one lodge] to a nursing home ... to another nursing home .... [then] they punch you into one that you haven't chosen because it's available and then ... the one you selected is now available so now you move across there .... it took ... 6 months to remember which door

> was his where he was living for a year, and to constantly move ... it's a real pain.

Other caregivers identified problems with the coordination of homemaking services, particularly when a new homemaker was initiated.

Two other aspects that were identified by the caregivers were lack of choice in formal helpers and limiting the involvement of the caregiver in providing care. Four caregivers referred to a lack of choice and these involved a lack of choice in selecting a physician, homemakers, and long term care facilities.

> The family haven't time to go and look at the facilities and say, oh well, I think we'd rather go here than there. You just go here and that's it.

Involvement in caregiving was important to most caregivers. When one caregiver's involvement was limited and he felt that the recipient's care was inadequate, he became very frustrated. He had bathed the care recipient every morning at home and the care recipient was now given a bath once a week:

> I'm even limited now of how much help I can provide him ah in an institution, how much they're willing to let me do. I don't think they want me to do it [bathing] on my own and I don't know if they even want me to do it period.

The caregivers also identified system characteristics that interfered with meeting the needs of the care receiver. These included inadequate staffing, policies that restricted the services provided, inadequate care standards, and the variations in cost or the high cost of service.

Seven caregivers referred to staff being insufficient in

numbers or inadequately prepared to meet the needs of the care recipient. In other situations, policies interfered with meeting the needs of the caregiver/receiver. For example, one care receiver was denied admission to a care unit because he was less than 65 years of age. In the case of homemaking services, one caregiver found the minimum time requirement was greater than the caregiver needed and another caregiver found that his needs did not match the service mandate:

> I really didn't need the housework done so much as I wanted time off .... I'd ask them to take [care recipient] for a walk .... for a while they objected to that because ... their bosses figured that they should be cleaning house.

Two caregivers questioned the standard of care that was provided. Two caregivers also identified the lack of appropriate facilities to handle aggressive behaviour and two other caregivers identified situations where the assessment of the care recipient was inadequate.

> He does not belong in a mental hospital. He belongs in a care home that can handle aggressive behaviour which we don't have in this country.

> they lock you up in a room or they put you into a room. They don't provide help eating, they don't provide help bathing, they ... just kind of watch over you. And for somebody with Alzheimer's I didn't think this was the appropriate treatment.

> they sent her home [from Emergency] at two in the morning ... so I had a tough week cause she was very weak and ah you know very hard to handle because of the deadness of her weight ... and I had quite a tough time. I almost gave up really.

> the nurse that assessed her had assessed her wrong ... out of desperation the head nurse phoned me and said ... the form said she wasn't incontinent ... she sounded so desperate I went and brought [care recipient] out again.

Four caregivers identified cost as a disabling factor. In two situations cost was a deterrant to obtaining additional help with care. In one situation the caregiver found that the cost of the same service from different agencies varied.

> they're different levels of money involved here ... some of them are quite reasonable ... some of them that are quite expensive ... [for] very similar service.

Another caregiver referred to institutionalization as being costly. Some caregivers, however, perceived the cost of the services they received to be very reasonable. Some caregivers were also pleased to pay for the services they received.

Outcomes

The overall outcome of the use of formal help was caregiver satisfaction or dissatisfaction. There were several intermediary results that contributed to caregiver satisfaction or dissatisfaction. These results involved feelings about accessing and using formal support, the perceived value of formal help, and the creation of a new life for the caregiver.

Feelings about accessing and using formal support. The feeling of concern was most apparent across caregivers. This concern was focused on the adequacy of care for the care recipients. The caregivers expressed positive feelings that included pleasure, appreciation, contentment, and confidence. The negative feelings included frustration, helplessness, uncertainty, displeasure, desperation, and shame.

The majority of the caregivers expressed positive feelings toward sources of formal support. The major sources

of formal support included homemaking services and other home-based supports, institutional care including both long term care, hospital, and mental health facilities, respite services which included day programs and short term institutional care, and formal support groups.

The caregivers spoke about homemaking as a service and also commented on individual homemakers. The caregivers expressed positive feelings about the service and about individual homemakers.

> She was wonderful ... wonderfully caring person.
>
> She really put out as far as help was concerned.
>
> She's very good at what she does and you feel very comfortable.

Although the feelings of the caregivers toward the service and individual homemakers were positive, some caregivers felt the system could be improved. For example, some caregivers felt that communication between service providers and consumers should be improved and one caregiver was angered by the abruptness of a supervisory staff person. One caregiver also described the sadness he felt in response to the personal situations of the homemakers he met.

The caregivers primarily expressed positive feelings towards sources of formal support in care facilities. These positive feelings were expressed by such comments as

> [the staff] are very supportive of the family as well as the patient.
>
> [the nurses] are phenomenal ... I don't know how they do their job, they're great.

[the staff] need all the medals in the world.

Some caregivers also mentioned specific formal helpers - a social worker, doctor, chaplain, recreational supervisor - who were particularly helpful. One caregiver was angry about the care provided and ashamed of the treatment provided. Once his care recipient was moved to a different setting he felt more positive about the care provided. Several caregivers also identified particular formal helpers (doctors, nurses) who angered or frustrated them.

Ten of the caregivers had experience with respite service but not all described their feelings toward the service. There were variations in the use of respite. For some it involved use of a day program one or more days a week; for others it involved admission to a care facility for a 2 week break periodically; others combined both forms of respite. Those who did express feelings about the service felt it provided a good break for the caregiver and care recipient. One caregiver reluctantly used a respite service in order to attend a family celebration in another city. He was so pleased with the care that he used the service again. Although he had been reluctant to consider institutional care, his experience with respite care made it easier for him to place his wife in a long term care facility when it was needed. Another caregiver alluded to his use of respite as a negative experience which caused him great concern when his wife was destined to be placed in the same facility permanently. Another caregiver retrieved his wife from the

respite facility because he felt the need to be with her there all day anyway.

Six of the caregivers had support group experience in a care facility or at the Alzheimer's Society. One other caregiver attended a community-based group meeting of caregivers arranged to elicit feedback about the service provided. Four of the caregivers found the experience was positive and three did not. The positive feelings were associated with obtaining pertinent information, being able to help others in the group, and being able to relate to others with similar experiences.

> I think there's a current of everbody's in the same boat ... so I think that's a bit of a strength builder as I think that there's a feeling that people can understand what each of us is going through.

The caregivers who did not find the support group experience helpful did not like talking in a group or could not relate to the members of the group. For example, some caregivers could not relate to other caregivers whose loved one did not have cognitive impairment or where the caregivers were adult children of the recipient.

> it's a different loss. They haven't really lost [like I have]

The feelings of the caregiver toward the support group also varied with the availability of other supports and the timing of the group participation. One caregiver who was grieving found that the group focused too much on problems. He felt more sadness in the group and embarrassed when he

cried; he preferred to spend this time in an activity unrelated to his problems. This caregiver had weekly counselling sessions where he expressed his feelings and shed tears without embarrassment. Another caregiver described not being able to relate to the discussion about institutionalization; later when he faced the same decision he wondered if the support group might help him. One caregiver also described another caregiver who perceived he didn't need the group until the time when his wife's condition deteriorated.

Perceived value of use of formal help. The caregivers identified the value of the use of formal support, often retrospectively. They recognized how formal help met their own needs and the needs of the care recipient, affected their health, and expanded their understanding of the system and the circumstances of other residents. One caregiver was particularly cognizant of the caregivers' needs: "the patient is the first priority, the caregiver should be close second." Although the positive effects of care for the care recipient were identified by the caregivers, the negative effects of treatment were also identified. For example, the undesireable effects of drug use were identified. In relation to health, caregivers identified signs of improvement in their own health or a resumption of healthier behaviours as a result of having more time for themselves. On the contrary, however, those caregivers who experienced conflict with formal helpers experienced added stress. Several caregivers became sensitive

to the experience of other residents who did not receive visitors; their concern and compassion for these people was evident. There was also a strong desire on the part of some caregivers to contribute by helping others and to improve the system for others.

Creating a new life. The caregivers gradually created a new life for themselves once the recipients were institutionalized. The caregivers were in different stages of accomplishing this process. For one caregiver, it continued to be a struggle:

> I don't know how you handle this. You should wash your hands and start your life over again type of thing. I guess it's hard for me.

Over time other caregivers demonstrated a new attitude toward life.

> I've realized that she's there being attended, the best of care that is available. I have a life to live, so get on and start living and don't sulk .... Meet people, do things ... I'm coming out.

The caregivers created this new life for themselves while maintaining commitment to their loved ones. The majority of caregivers became more socially active with friends and family and resumed recreational activities. While some resumed prior relationships, others established new relationships, often with those who shared a caregiving experience or loss of a spouse. Some caregivers became more active in the Alzheimer's Society and one caregiver identified that he had moved beyond relating to others in the Alzheimer's Society.

> one of the problems I have now with the Alzheimer's Society is that ah they're talking about a lot of things

that have happened to me ... years ago.

Hiring Supplementary Help

Seven of the caregivers hired help to supplement the formal help provided to them. The caregivers hired help to care for the recipient at home as well to supplement the care provided in a care facility. In the home, help was hired for housekeeping duties or to care for or supervise the care recipient in the caregiver's absence. In a care facility, one caregiver hired help to supervise the care recipient during the night when his behaviour was difficult for the staff to manage. Another caregiver hired a nurse to care for his father following eye surgery. Another caregiver hired two women to attend to feeding and caring for his wife in the long term care facility on days when he did not visit.

The circumstances surrounding hiring practices varied. Two of the caregivers, both of whom worked in the business world, hired help like a business arrangement.

> anything else I wanted in the way of help, um I went out and purchased ... I went out as if I was running, just like I'm running a business and I need it, I went out and bought it, like nursing help, care dropping in, and this sort of thing.

Three of these caregivers had an income of more than $40,000 and 4 of the caregivers had an income of $20,000 to $40,000. None of the caregivers with an income of less than $20,000 hired help.

Summary

The process of using formal help with care has been described wherein the caregiver yielded reluctantly to the

involvement of formal help. The process involved resisting, giving in, opening the door, and making the match. In making the match, the caregiver engaged formal help, redesigned the caregiver role, and was influenced by both enabling and disabling behaviours and system characteristics. As a result, the caregivers expressed feelings about accessing and using formal support, identified the perceived value of using formal support, and created a new life for themselves. The overall outcome was caregiver satisfaction or dissatisfaction. Some caregivers also hired help to supplement the formal help provided.

One caregiver in the sample did not use any formal support at all. The primary difference between this caregiver and the others in the sample was that he did not yet have a critical experience to prompt him to use formal help. He identified that if his wife were to lose her bowel function, he would feel the need to seek formal help. He also had informal help that provided the kind of assistance that others received from the formal network. For example, his daughter looked after some housekeeping responsibilities and personal care of her mother. This caregiver also obtained information from people in his informal network who had medical expertise. Like other caregivers, his need for formal help was associated with the amount of help available from his informal network and the adequacy of this help to meet caregiver / receiver needs.

Meaning of the Role

The meaning of the caregiving role to the caregiver is a relevant aspect of the data analysis. There may be an association between the meaning of the role ascribed by the caregiver, his feelings about asking for help, and his willingness to use formal support.

The meaning of the caregiving role may be described in the terms used by the caregivers or in relation to the feelings and behaviours they demonstrated in their caregiving activities. The words used most frequently by the caregivers were variations of responsibility, love, obligation, and protection.

> I said we were responsible for grandma as it's time we owned up to that and brought her up her and took care of her.
>
> She's my mother and I love her.
>
> I love that woman.
>
> I thought I had an obligation, a moral obligation.
>
> We've got to be more protective of him than we were before.

Other words included commitment, dedication, satisfaction, opportunity, and purpose. Examples of the caregivers beliefs included the view that their caregiving was of direct value to the well-being of the care recipient, the care recipient would do the same for the caregiver if the situation was reversed, and that caregiving was an opportunity to repay the care recipient. They feared the possibility of not being available to the care recipient if the care recipient outlived them.

> I also have the idea in the back of my mind that my continued presence, my continued fussing about is holding back the progression of the disease.
>
> this is really part of my daily routine and ah, and I wouldn't think of it any other way. And I know, like she was my best friend and ah she would do the same for me.
>
> I'm just hoping to God I don't go before she does. And that worries me more than anything else, that's a major concern of mine. If something happens to me, then where is she.

Although the caregivers expressed their feelings of frustration, anguish, and exhaustion they also primarily described the meaning of their role in positive terms. This meaning was often linked directly to their perceptions of the meaning of their relationship.

> he's got nobody, there's only the two of us [brothers] left and ah he's got nobody but me so I didn't want to let him down.
>
> How I came to be looking after her is simply because I'm her husband and she's my wife.

The association between the meaning of the role to the caregiver and the caregiver's feelings about asking for help is of interest. Of the 4 caregivers who stated they had no difficulty asking for help, none used terms like responsibility, obligation, or protection to describe their role. Further examination of the association between the meaning of the caregiving role, help-seeking, and use of formal help is required.

Meaning of Support

Although the meaning of support to the caregivers is reflected by their feelings and actions, the caregivers were also asked directly about the meaning of support to them. The

responses to this question add to what is inferred from their feelings and actions and provide a further context in which to understand their reluctance to use formal sources of support.

The caregivers' responses about the meaning of support pertained to both formal and informal support. Some caregivers experienced difficulty answering the question; most caregivers provided an example to exemplify the meaning of support. The responses included examples of practical assistance, emotional / affirmational assistance, and receiving information.

The caregivers identified several kinds of practical assistance. Nine of the caregivers mentioned the financial aspect of support, most often citing a personal example of giving money to their children, or in fewer cases, their children giving money to them. Other kinds of practical assistance included assisting the caregiver with care, relieving the caregiver, visiting the care recipient, providing resources to help with care, and helping with shopping, meals, and transportation.

The emotional / affirmational assistance involved demonstrating concern for the caregiver as well as the care recipient. This included maintaining contact with the caregiver, offering encouragement and praise, showing sensitivity for the caregiver's needs and feelings, and providing opportunity for the caregiver to talk about his situation. It also involved relating to others with similar experiences, having opportunity to be involved in activities

not related to caregiving, and knowing that help would be available if needed. In relation to the care recipient, the caregiver valued inquiries, acceptance of limitations, and visits.

With respect to information, the caregivers primarily identified information related directly to the care recipient as helpful. They valued the opportunity to ask questions and seek advice. It was also helpful when formal helpers demonstrated knowledge about the care recipient as an individual.

Not all caregivers valued the same kind of support. One caregiver valued relief from caregiving over encouragement or praise for the care he provided. Another caregiver valued connection with others as most important. Some of the caregivers identified a universal aspect to support. "You can't live in this world without asking for support. I think everybody has to have support from somebody." This universal perspective contasted with the belief expressed earlier by many caregivers that they could provide care for their loved ones independently.

In conjuction with their perceptions of the meaning of support, 12 caregivers commented on the family's obligation to support its members. These caregivers felt there was some obligation for family members to help one another in times of need and one caregiver even used the term "family ethics". A few caregivers also identified priorities in obligations among family members, citing the greater priority was to one's

spouse as opposed to the obligations of adult children to their parents.

The responses of the caregivers about the meaning of support reflect some of their values and beliefs. The caregivers valued different kinds of support and many caregivers believed the family has responsibility to support its members. These values and beliefs may influence the caregivers' use of formal support.

Chapter 5

Discussion

The process of making concessions for care, identified in this study of male caregivers, is reflected in aspects of caregivers' experiences reported in the literature and is associated with what is known about individual and family behaviours. This discussion will focus on (a) particular aspects of the caregivers' experience in making concessions for care, (b) a comparison with processes of caregiving identified in other qualitative studies, and (c) relevant theoretical perspectives. First, the discussion will focus on particular findings: personal and system barriers, supportive behaviours of formal helpers, nonsupportive behaviours of formal helpers, and nonsupportive system characteristics.

Making Concessions for Care - Particular Findings

Personal Barriers

The reluctance of the caregivers to use formal help may be explained by the personal values and characteristics of the caregivers that influenced their help-seeking behaviour. The caregivers provided several reasons why it was difficult for them to ask for help - independence, responsibility, pride, and inexperience in asking for help. The desire to extend their independence into the caregiving role coupled with their inexperience in asking for help, feeling too proud to ask for help, and a sense of personal responsibility, reflects a strong sense of self-reliance within the group. This norm of self-reliance and individuation leads men to perceive help-

seeking as an admission of incompetence (Belle, 1987).

Another reason cited by caregivers for not asking for help was a feeling of obligation to do something in return. This feeling may be explained by the moral norm of reciprocity (Gouldner, 1960), a fundamental force in social life "which defines certain actions and obligations as repayments for benefits received" (p. 170). From studies on support and reciprocity reviewed by Uehara (1995) there was evidence that

> people feel obligated to return benefits they receive from others, appear to be more psychologically and emotionally averse to overbenefiting than underbenefiting from social support interactions, and tend to avoid placing themselves in the position of 'overbenefitors' (p. 483).

The caregiver possibly perceived himself as overbenefiting from formal help and thus preferred to manage care independently or to hire help, if he was able.

Values associated with family relationships may also influence the caregiver in his help-seeking behaviour. The meaning of the caregiving role to the caregiver was described in terms of responsibility, commitment, obligation, protection, or an opportunity to repay the care receiver. King, Collins, and Liken (1995) described values that affected the caregivers' use of community resources: family obligation to provide care, family ownership of difficulties, family protection of vulnerable members, and family self-reliance. The similarities between these family values and both the

reasons for having difficulty asking for help and the meaning ascribed to the caregiving role, are striking. Similarly, Stephens (1993) identified the sociocultual and family context as an integral component in caregivers' decision-making about utilizing formal services.

The issue of control may also be associated with male caregivers' reluctance to use formal help. The use of formal help, particularly institutional care, involves relinquishing control of care to others. The male caregivers in this study were most concerned about the adequacy of the care for their loved ones. Relinquishing control of this care may have threatened their ability to ensure that the care provided was acceptable. Likewise their desire to maintain involvement in care may be related to ensuring some control over the quality of this care (King et al., 1995). Male caregivers are also known to take control more readily than women in the caregiving role, which may be an extension of their roles established at home and at work (Miller 1987).

There are other reasons cited in the literature as well that are associated with resisting the use of formal help. Caregivers may wish to maintain the image of the "idealized caregiver" (Dellasega & Mastrian, 1995). The image of what is ideal may relate to those individual and family values held by the caregiver. Likewise, relinquishing care to an institution may represent failure to the caregiver (Dellasega, 1991). The caregiver's view of institutionalization as either a stressor or coping mechanism (Townsend, 1990) may also influence his

feelings toward relinquishing control. Prior experience with institutional care may influence the caregiver's perception just as prior experience with respite care influenced the caregivers in this study.

Although the purpose of this study was to explore male perceptions rather than to compare male and female perceptions of support, the question arises: Do the experiences of these men differ from the experience of women in the same role? There is evidence to suggest that both genders may be reluctant to involve formal support. Generally, there is more of a tendency for caregivers to use resources once a crisis occurs (Montgomery & Borgatta, 1989) or when caregiving responsibilities become too intense for the caregiver to handle alone or with informal help (Neary, 1993). Cossette, Levesque, and Laurin (1995) found more similarities than differences between genders in their use of formal and informal support. The process of relinquishing control in the caregiver role is not unique to men (Willougby & Keating, 1991) and the values associated with family relationships are shared by men and women (King et al., 1995). Studies of male caregivers report their infrequent use of formal support (Kaye & Applegate, 1990; Vinick 1984) but other studies indicate male caregivers receive comparatively more help with tasks (Horowitz, 1985a). The question remains as to whether some values or characteristics are more operational with each gender.

System Barriers

The most predominent barrier identified by the caregivers in accessing the formal system was lack of information and not knowing where to go for help. Lack of knowledge of services was also the most frequently cited barrier in Stephens' (1993) study of the caregiver's use of formal services. Neary (1993) also acknowledged the complexity of accessing community resources and the difficulty for older adults who may find the process intimidating.

Supportive Behaviours

The enabling behaviours of formal helpers that provided power, skill, or resources to the caregiver were essentially those behaviours that he perceived as supportive. These behaviours of formal helpers - comforting the caregiver, demonstrating a caring attitude, addressing problems, affirming the caregiver's role, providing assistance with caregiving, and providing information - demonstrated empathy or were esteem-enhancing. These enabling behaviours of formal helpers were dependent upon the development of a meaningful relationship with the caregiver.

Three of these behaviours were also identified by Duncan and Morgan (1994) as significant to caregivers: staff showing sensitive and professional behaviours toward both the resident and family, staff showing recognition of the caregivers' prior experience in providing care, and staff accepting caregiver involvement in care. Empathy, a key ingredient in the helping relationship (MacKay, 1990), may be perceived by the caregiver

when staff show sensitivity toward the resident and family. Recognition of the caregiver's expertise and involvement in care may be esteem-enhancing, which Heller et al. (1986) consider to be the primary component of perceived support and the aspect of support most closely associated with health. The caregivers' need for esteem-enhancement is understandable particularly in light of the possibility that they may have compromised individual and family values by conceding care to the formal system.

Nonsupportive Behaviours and System Characteristics

Of equal significance are those behaviours and system characteristics perceived by the caregivers as disabling or nonsupportive and even detrimental. Contrary to enabling behaviours, disabling behaviours demonstrated a lack of empathy from formal helpers or reduced the esteem of the caregiver. Disabling characteristics of the system interfered with the caregiver's goal of securing and sustaining an acceptable quality of care for the care recipient.

The presence of conflict in relationships with formal helpers was a direct result of disabling behaviours or system characteristics and resulted in stress and dissatisfaction. The presence of conflict was significant in that it represented a negative dimension to support that may have a more powerful effect on health (House, Umberson, & Landis, 1988; Rook, 1990) than the more general benefits of support (Stewart, 1995). This powerful effect may account for why the caregivers focused more on those system characteristics that

were disabling rather than on those that were enabling.

The individuality of the caregivers was evident in their responses to resources and their need for a variety of different supports to meet their needs. For example, the use of formal support groups was not perceived as beneficial to all. Support groups that focus only on ventilation of feelings and discussion of problems may not alleviate the caregiver's burden (Pratt, Schmall, Wright, & Hare, 1987); most effective groups help with problem-solving and developing strategies for dealing with difficult situations. In addition "homogeneity of problems" facing participants has been identified as significant to self-help group success (Lieberman, 1985). In the present study, one caregiver found the support group added to his feeling of burden and others could not relate to the issues being discussed.

Support was derived from a variety of professionals and paraprofessionals. Some of those caregivers who were able to achieve satisfaction with their altered caregiving roles had one professional who provided them with continued opportunity over the long term to express their feelings and concerns. This finding emphasizes the importance of the development of a meaningful relationship with one professional to whom the caregiver can relate (Kaye & Applegate, 1990).

Many of the consequences of the use of formal support identified in the literature relate to institutional care. Stephens et al. (1991) found that the primary relief that resulted from institutional care was in terms of caregivers'

social lives rather than in terms of their mental and physical health; in the present study the caregivers' reported an improvement in their social lives and some also perceived their health to be better. That stress is not reduced following institutional placement or may even be exacerbated (Pratt et al., 1985; Stephens et al., 1991), may be explained, in part, by the presence of enabling and disabling behaviours of formal helpers and characteristics of the system. Those caregivers who perceived the presence of enabling factors expressed satisfaction with the care provided and the decisions they made in their caregiving role. The caregivers who perceived a predominance of disabling factors experienced more conflict, stress, and dissatisfaction with the care provided and the decisions made as caregiver.

Process of Caregiving - Other Qualitative Studies

The findings described in this study resemble the processes identified in other qualitative studies. These studies focus on the process of providing care for a relative with dementia, the process of institutionalizing a relative with dementia, and the experience of caregiving men.

Wilson (1989) identified the basic social-psychological problem in caring for a family member with dementia as coping with negative choices. Three stages are identified in the process: taking it on, going through it, and turning it over. In the second stage, caregivers encountered obstacles which included their own feelings of embarassment and lack of information for obtaining help. Like the caregivers in the

present study, they gave all they could to the caregiving role before seeking help. In the final stage the caregiver came to terms with a decision to give up control of care, though remained involved in "invisible caregiving" and encountered problems of visitation. These latter events are encompassed within the phase described as redesigning the caregiver role in the present study.

One of the most important negative choices described by Wilson (1989) was the decision to use institutional care. The caregiver's resistance to institutionalize the care recipient and the need to convince himself that institutional care was best, sometimes even after the decision was made, is supported by Wilson's description of the negative choice.

The phases described by Wilson (1989) are similar to the three phases described by Lindgren (1993) in her description of spousal caregiving as a fatalistic career. The encounter stage, which involves diagnosis and initial caregiving experiences, parallels the phase of resisting identified in the present study. The enduring stage, in which the caregiver provides extensive care and copes with social isolation and mental distress, encompasses the stages of giving in, opening the door, and making the match. Like the phase identified as 'giving over' in the present study, the final stage described by Lingren involves relinquishing some aspects of care through institutionalization. Similarly, she reported that caregivers remained involved in care following institutionalization. The present study provides an amplification of the caregivers'

perceptions of the process of accessing and using the formal system.

Morgan and Laing (1991) focused on spousal perspectives in relation to the diagnosis of Alzheimer's disease. Two groups of caregivers were identifed: those who were motivated by love and experienced grief and those who were motivated by responsibility or duty and experienced role strain. The couple's previous relationship determined the caregiver's response. Those caregivers in the grief group were more open to the use of community services whereas those caregivers in the role strain group resisted the use of support services. The authors propose that the difference may be explained in terms of subjective and objective burden. Those caregivers in the role strain group experienced more subjective burden and perceived that community support services would not relieve this burden. In the present study it is not possible to confirm whether the caregivers who described their prior relationships as loving and strong also sought formal sources of support more readily. One particular caregiver in the present study, however, who was devoted to his wife and perceived caregiving as an opportunity to repay her, also did not hesitate to seek formal help. Further exploration of the association between the meaning of the relationship to the caregiver and his willingness to seek formal help is warranted.

Dellasega and Mastrian (1995) examined the process and consequences of institutionalizing an elder. The caregivers

perceived the decision to be theirs alone and professional input was not helpful. The weight of the responsibility for the decision to use institutional care is also reflected by the caregivers in the present study; however, some professional involvement was perceived as helpful. The consequences of the decision to use institutional care are similar in both studies: emotional turmoil and ambivalence (convincing yourself) and role redefinition (redesigning the role).

In their study of 10 family members who had placed a relative with Alzheimer's disease in institutional care, Willoughby and Keating (1991) identified a five-stage model of gaining and relinquishing control of caregiving. The stages resembled those identified in the present study. No professional help was used in the first stage. The caregivers made their own decisions in the second stage but also acknowledged the need for more help. The caregivers accepted the involvement of professional help in the third stage but after an accumulation of events over time (as opposed to a single event). The fourth stage of adjusting to the psychiatric institution reflected negative caregiver feelings - helplessness, frustration, and lack of control. In the final stage the caregivers moved on to taking control over their own lives (creating a new life) and letting go of the focus on caregiving. Like the present study, Willougby and Keating note that the caregivers moved to the next stage only when they felt they had reached the limits of their abilities

to manage. The present study differs in that it explicates the sequence of events involved in using all formal help and it identifies both the personal and system barriers encountered by the caregiver as well as the caregivers' perceptions of enabling and disabling factors which influenced the process.

The qualitative study by Opie (1994) addressed caring from the perspective of behaviours and emotional attitudes. Opie revealed a spectrum of behaviours and attitudes that are based on dimensions of love/hate or indifference. Caregivers demonstrated commitment, obligation, dissociation, or repudiation in their relationships with care recipients. As in the present study, at the heart of commitment was the caregivers valuing the past and present relationship and believing in their ability to have a positive effect on the care recipient in spite of the level of impairment. Obligation referred to caring as a duty rather than a desire to sustain the relationship. Dissociation referred to continuing to care accompanied by restriction on involvement. Repudiation, on the other hand, was characterized by anger, fear, and resentment at having to care while not wanting to care. In the present study the majority of caregivers demonstrated commitment or obligation though elements of dissociation and repudiation are also evidenced.

Other qualitative studies focused only on male caregivers. Like the characteristics of many men in the present study, Motenko's (1988) study of 6 male caregivers

found that caregiving was a labor of love, a source of pride, a demonstration of commitment, and an opportunity to reciprocate. Caregiving afforded the men an opportunity to exercise control, mastery, and competence. Formal help with care was accepted only as a temporary means to enable the caregiver to maintain his caregiving role and only to those who could be trusted to meet the caregiver's standard of care. Respite care, which primarily involved the use of home health aids to assist with care, was viewed as assisting the caregiver to act responsibly. Respite care was not used for longer terms of relief. Unlike the present study, Motenko's sample of caregivers included only one spouse with dementia. It may be that behavioural changes associated with dementia influence the amount of mastery and competence experienced by caregivers, their need for longer terms of respite to maintain their caregiving role, and their views of themselves as protectors.

Harris (1993) identified four types of caregivers from among a sample of 15 male caregivers whose wives had Alzheimer's disease: (a) the worker group who fashioned their caregiving role after their work role, (b) the labor of love group whose devotion to their wives predominated, (c) the sense of duty group whose role emphasized commitment, duty, and responsibility, and (d) the group at the crossroads who were new to caregiving and uncertain about what to do. The descriptions parallel the role descriptions given by the caregivers in the present study. The last group is reflected

by the caregivers' accounts of how they felt at the beginning of their caregiving experience.

Archer and MacLean (1993) also investigated the meaning of the caregiving role with 6 male caregivers, two of whom had wives with Alzheimer's disease. These men used outside interests in order to cope with their caregiving responsibilities and all received a sense of satisfaction from the caregiver role. Some of the men in the present study were able to maintain involvement in outside interests; others were prevented from doing so due to the caregiving demands and many had to give up outside interests until their care recipients were institutionalized.

Vinick (1984) interviewed 15 widowers who had cared for their wives and found there was expressed reluctance to place their wives in a nursing home and a minimization of the hardships they faced. Like the men in Vinick's sample, the men in Kay and Applegate's (1990) study did not often use formal service and "they appeared to restrain their usage even as their own health and functional status were on the decline" p. 60. Both of these studies took place in the United States; the effect of the health insurance system, which may have affected the use of formal support, is not known. However, the reluctance of men in the present study to involve formal supports is similar to the behaviours described by Kaye and Applegate and Vinick.

Theoretical Perspectives

Several theoretical perspectives may be relevant for

understanding the help-seeking behaviours of the caregivers. The process of making concessions for care will be explored with respect to several theoretical perspectives: development associated with gender, equity, a model for community service use, decision-making, and planned behaviour.

Development Associated with Gender

One author (Gilligan, 1982) proposed that moral development among men is based on an ethic of rights that relies on justice and balancing the needs of the self and others while moral development among women is based on an ethic of responsibility that gives rise to responsibility and care. Masculinity, defined through separation of self from one's mother due to gender differences, is focused on self-reliance and individuation while feminity, defined through attachment, is focused on relationship with others. Gilligan's account of moral development does not support the experience of male caregivers in this study with respect to their focus on responsibility and care. When emphasis is turned toward male self-reliance and individuation, however, Gilligan's account does support the male caregivers' experience in being reluctant to seek the help of others. The theory is also supported with respect to fairness and the opportunity described by some men to repay their wives. Although development with respect to gender roles may impact upon the salient values and beliefs that affect the caregiver's help-seeking behaviour, this theory falls short in explaining *how* these beliefs affect help-seeking behaviour and

why most caregivers (both male and female) of relatives with dementia use relatively few community resources.

Equity

Equity theory (Walster, Walster, & Berscheid, 1978) provides another possible explanation. According to equity theory, society prompts individuals to behave equitably by rewarding behaviour based on equitable use of resources and punishing behaviour that involves an inequitable distribution of resources. When individuals participate in inequitable relationships, they feel distressed. Several caregivers indicated that they perceived caring for their wives as an opportunity to repay their wives for care provided in the past, thus adding balance to the perceived inequity within the relationship. The caregivers possibly also perceived an inability to reciprocate with formal service providers, thereby creating an uncomfortable imbalance. The reason some caregivers preferred to pay for help from formal sources could be explained by their need to avoid indebtedness.

Model for Community Service Use

Further understanding may also be provided by a model for understanding community service use among family caregivers of Alzheimer's patients (Collins, King, Given, & Given, 1994). In this model the major outcome is the family's *intent* to seek service. When the caregiver decides to use service, factors within the actual service delivery system such as availability, affordability, and quality of the service will influence *actual* service utilization. The intent to seek

service is influenced by caregiver/patient attitudes and internal and external cues.

The caregiver/patient attitudes identified in this model include caregiver independence, caregiver fears, and caregiver attributions about the preferences of the care recipient regarding service use. These attitudes are supported in the present study. Independence is a significant factor identified by the caregivers in their reluctance to seek help. Some caregivers expressed concerns (fears) about the quality of care provided by the formal system. A few caregivers alluded to having discussed the possibility of institutional care with their care recipient and acknowledged their determination to provide care at home as long as possible.

The internal cues to action include the adequacy of informal supports available along with the caregiver's physical and emotional health and perceived competency in managing the care recipient. In the present study, no formal support was used by the caregiver whose daughter provided the equivalent of homemaking service and personal care for the care recipient and whose social network provided him with the opportunity to obtain information available to most others only through the formal system. Other caregivers in the present study acknowledged their own health or incapacity to continue to provide the level of care required by the care recipient as reasons that prompted the decision to seek care.

The external cues to action include public sources of information, referrals from health-care professionals, and

suggestions provided by the informal network. A public source of information for most caregivers in the present study was absent and constituted a barrier for the use of formal support. Once the caregiver sought help and connected with a link to formal help, professional referrals were provided; however, in the present study professional referrals occurred only after the caregiver had accessed the system. This access was both by seeking help within the community or as a result of hospitalization. Suggestions provided by the informal network were not explicated within the present study.

In the model proposed by Collins et al. (1994), the availability, acceptability, and affordability of the service also influences the caregivers' intent to seek services. In the present study, these service attributes had a bearing on the caregivers' engaging formal help in the phase of making the match, but did not have as explicit an effect on initial help-seeking behaviour as personal attributes did. With few exceptions the experiences of the caregivers in the present study fit the model for community service use developed by Collins et al. (1994).

Decision-making

Further understanding may also be provided by Stephens' (1993) framework for conceptualizing service use from the caregivers' perspective. This framework is based upon a cognitive decision-making approach by which the caregiver processes information about the self, significant others, and the formal service sector. Based on caregiver and other role

experiences, the caregiver makes a judgement as to the presence of psychosocial distress. In the presence of distress, the caregiver is influenced by sociocultural, family, and service system contexts in determining whether or not to seek help. This framework offers general support for the caregiver's self-appraisal of the need for help and the influence of personal, family, and system factors in the initial and subsequent decisions to use formal help.

Janis and Mann's (1977) decision-making model provides yet more clarity with respect to the process of deciding to seek help. Careful decision-making involves weighing the gains (or benefits) against the losses (or costs) (Mann, 1972). The consequences of the decision are judged for the self and significant others with respect to both gains or losses and approval or disapproval (Janis & Mann, 1977). The caregivers waited to seek help until a critical experience tipped the scale; the benefit of seeking help outweighed the cost. The decision to use institutional care was also a process of weighing the benefits and costs. During this time the caregiver was engaged in a process of convincing himself that the benefit of using institutional care outweighed the cost. As in the framework proposed by Stephens (1993), both the individual caregiver and significant others are influential in the decision-making process. This decision-making framework and the model proposed by Collins et al. (1994), however, are insufficient with respect to understanding *how* individual and family beliefs influence

decision-making.

Planned Behaviour

The Theory of Planned Behavior (Ajzen, 1985; Ajzen & Madden, 1986; Madden, Ellen, & Ajzen, 1992) provides a general framework for understanding the relationship between personal beliefs, attitudes, and behaviour. This theory is based on the Theory of Reasoned Action first proposed by Fishbein & Ajzen (1975). In the Theory of Reasoned Action, behavioural intention is the immediate antecedent of behaviour. The two distinct determinants of behavioural intention include the individual's attitude toward the behaviour and subjective norm, a social factor that pertains to perceived social pressure about the behaviour. The antecedents of attitudes and subjective norms, which are behavioural beliefs and normative beliefs, are also identified.

The Theory of Planned Behavior extends the Theory of Reasoned Action by adding the dimension of perceived behavioural control which is the individual's belief about how easy or difficult it will be to perform the behaviour. Beliefs about resources and opportunities determine perceived behavioural control. Perceived behavioural control, like attitude and subjective norm, influences behavioural intention. In addition, perceived behavioural control may also directly influence the performance of the behaviour, without the intermediate effect on intention. The nature of the effect of perceived behavioural control is dependent upon the amount of volitional control present in the situation. A

positive attitude and/or subjective norm and perception of the presence of control leads to a stronger intention to perform the behaviour.

This theory supports the association between the caregivers' personal beliefs about independence, responsibility, and obligation and their behaviour (reluctance to ask for help). That some of the reluctance to seek help stems from the influence of such normative family beliefs as family privacy and obligation, is also supported. The caregiver's reluctance to relinquish control, particularly if he perceives the outcome of care provided by the formal system to be less that the quality desired, is also supported by this theory.

The Theory of Planned Behaviour presupposes that external variables influence behaviour only through their impact on beliefs. Altering beliefs is a complex process and may account for the continued resistance to seeking formal help. The process experienced by the caregivers, making concessions for care, denotes a giving up of something valuable. In addition to yielding to the involvement of formal help in care, modifying beliefs may be central to the caregiver's struggle.

The Theory of Planned Behaviour also complements the explanations of caregiver behaviour provided by the other theories previously described in this chapter. Sex roles may influence the development of beliefs. Individual, family, and societal experiences influence beliefs and may account for

some differences within genders and similarities across genders. The caregiver's beliefs about equity may also influence his behaviour. Finally, in the decision-making process, the cost of conceding to behaviour that differs in some way from one's behavioural, normative, or control beliefs may be weighed against the benefits. Furthermore, the fact that some caregivers had no difficulity asking for help, a function of their individual, normative, and control beliefs, is also supported by this theory.

The Theory of Planned Behavior is useful in furthering our understanding of the caregivers' help-seeking behaviour in relation to beliefs, attitude, subjective norm, and perceived control. It stops short of understanding the development of belief systems, explaining why some beliefs are more important to some individuals than others, and demonstrating how beliefs can be modified to influence behaviour.

Implications

Practice

There are several personal and system level implications for practice that arise from this study. First, professionals must be sensitive to the impact of individual values and beliefs upon the help-seeking behaviour of the caregiver. The formal support offered must fit within the context of the caregiver's belief system, to the extent possible. Processes must be developed to assist in the assessment of individual and family beliefs, and where necessary to protect individual and family health by relieving caregiver distress, processes

must be developed to modify individual and family beliefs. Assessment ought to include a determination of the amount of control desired by the caregiver when formal supports are used. Strategies that permit the exercise of control ought to be used, when the caregiver desires control. Efforts must also be made to foster behaviours among professionals and staff that convey empathy and enhance caregiver esteem.

Professionals must reduce system barriers that make access to formal care difficult and fragment the delivery of coordinated service. In particular, strategies to enhance public awareness of how to access resources are required. At the very least, the system must provide the caregiver with the means to establish a meaningful relationship with one professional who can guide the use of formal care, in keeping with the needs and desires of the caregiver. Professionals must also acknowledge that a variety of formal supports are required to meet caregiver / recipient needs and that the type and timing of service are important in making an effective match. Efforts must be made to streamline the process of long term placement to avoid fragmentation of care and to enhance coordination. Professionals must be prepared to facilitate the development of a new role for the caregiver, particularly when institutional care is used. Opportunity for family caregivers to evaluate formal services and voice their ideas and concerns in policy-making is also essential.

Research

There are several implications for future research that

arise from this study. A qualitative study that singularly focuses on the exploration of caregivers' perceptions of accessin and using formal support is necessary to confirm and extend the findings of this study. All participants should be invited to address each aspect of the process of accessing and using formal support to substantiate and extend the findings of this study. The findings present in this study could provide a basis for guiding questions in this research. In other research, the process experienced by male caregivers might also be compared with the process experienced by female caregivers.

A study that focuses primarily on the identification of values and beliefs of caregivers and invites their perceptions about how values and beliefs influence their own help-seeking behaviours would extend understanding of the experience. In-depth exploration of predominant values would further add to our understanding of their origin and meaning. A comparison of these perceptions between genders would be helpful. Of equal interest is identification of caregivers' perceptions of how they overcame personal barriers that prevented them from seeking help. The perspective of caregivers who have not yet sought help from the formal system could also provide valuable insights.

Other contextual factors that influence help-seeking behaviour should be explored further as well. These factors should include the meaning of the relationship between the caregiver and care receiver as well as the influence of

informal support in association with help-seeking from the formal sector.

The system barriers encountered by caregivers warrant further study. Evaluation research is needed to determine the effectiveness of strategies to reduce such barriers as lack of information about how to access and use the formal system. Further study of the nature of conflict with sources of formal support would also provide valuable information about the caregiver's struggle and how the formal system can be enhanced to meet his needs.

Study Limitations

This study is limited in that it was not possible to use theoretical sampling in the collection of data from caregivers that pertained to formal support. In the original study, however, each interview was reviewed in preparation for subsequent interviews. Due to the use of secondary data analysis it was not possible to obtain participant feedback about the process identified. Many of the caregiver responses pertained to both informal and formal support, thereby restricting the interpretation of results; in reality it may also be difficult for caregivers to distinguish between the two but effort toward this end is needed. Not all participants addressed all aspects of the process of making concessions for care but the data that is available fits the process and no part of the process is unsubstantiated by the data. In secondary analysis, misinterpretation of the data due to the researcher's distance from the data is a potential

limitation. This was overcome, in as much as is possible, by the use of contextual information to enhance interpretation and the guidance of the thesis supervisor who is familiar with the data. In addition, sample bias must be acknowledged. By virtue of self-selection in volunteering to participate in this study and the limitations imposed by the characteristics of this group of men, this study sample cannot be held as representative of all male caregivers.

Conclusion

There are no other studies known to identify the overall process experienced by male caregivers in relation to formal support. The unique contribution of this study is its focus on male caregivers' perceptions of formal supports and the identification of the personal and system factors that are associated with resisting the use of formal support. These factors include the values and beliefs held by the caregiver and family, the behaviours of the professionals and staff who work with the caregivers, and the situations that arise within the formal system that influence the caregivers experience. The caregiver's access to and use of formal support is a dynamic and complex process. The voice of male caregivers of relatives with cognitive impairment provides valuable direction for professionals who seek to meet their needs.

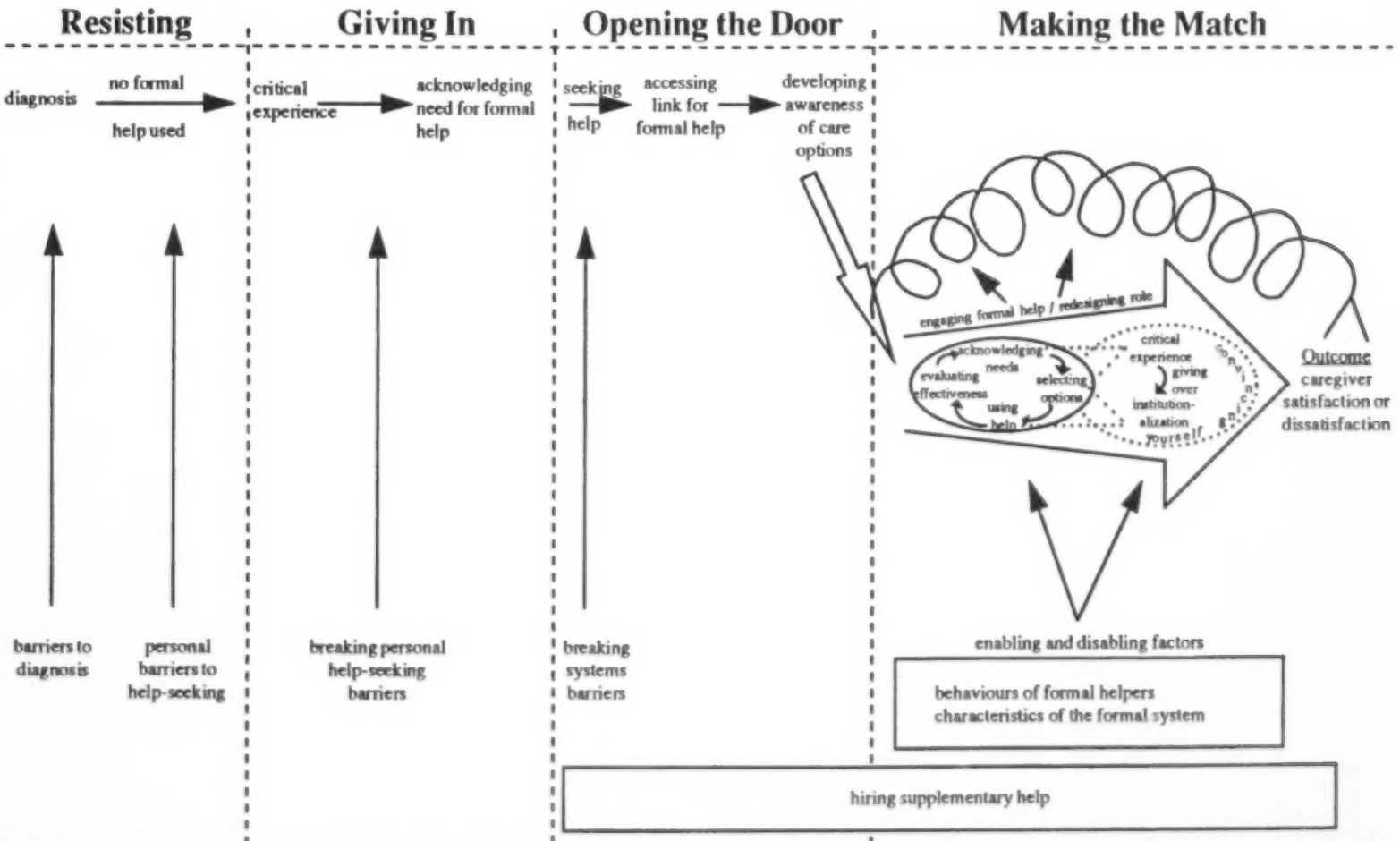

Figure 1. Making concessions for care.

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APPENDIX A

Guiding Questions for Interviews

Initial Interview

Introduction

1. Please tell me the story of how you came to care for ...
Probes: What are some of the examples of specific situations in which you experienced help (support) when you first started caring for ...? Please describe who was involved and what they do to assist you.

Caregiving Relationship

1. What is a typical day like for you in caring for ...?
2. In describing your relationship with (dependent adult) what do you contribute to the relationship? What does ... contribute?

Support Within the Social Network

We are interested in the support you receive in general not only the support that you receive in giving care to ...

1. During the past few weeks what are some of the examples of specific situations in which you experienced help (support)? Please describe who was involved and what they did to assist you.

2. From which relationship(s) do you receive most of your support or help? How would you describe these relationships (e.g. length of involvement, type of support, frequency of contact, difficulties)?

3. During the past few weeks while you have been caring for (dependent adult), what are some examples of specific situations in which you have given help to other people besides (dependent adult)?

4. How would you describe those relationships within which you provide most of the help in terms of length of involvement, type of support, frequency of contact, difficulties (other than relationship with dependent)?

5. Are you sometimes hesitant to accept or ask for help? If yes, please describe the situation.

Are you sometimes hesitant to offer help? If yes, please describe the situation.

Some of the people we have talked to have discussed non-support. Have you experienced non-support? Please describe who was involved and why you found them non-supportive.

Summary: Is there anything else in regard to support that we haven't talked about that you would like to share with me?

Demographic Data

In order to describe the men who have participated in the study, we would like you to answer the following questions:

1. What was your age on your last birthday? Years ____

2. Indicate by an X the amount of formal education you have.
Less than Grade 12 ____
Grade 12 ____
Some university or post-high school diploma ____
university degree ____
graduate degree ____

3. Into what category would you place your yearly family income?
Less than $20,000 ____
$20,000 to $40,000 ____
Over $40,000 ____

4. What is your current or past occupation? _____

5. Please indicate which of the following difficulties apply to the person you are caring for:

a) Please mark with an X each of the major difficulties which the person you care for experiences.
unaware of the time ____
unaware of where they are ____
unaware of who is around them ____
forgets events in the recent past ____
forgets events in their early life ____

b) Do you live with the person you are caring for? ____
c) What is your relationship to the person you are caring for? _____

Follow-up Interview(s)

Individualized Questions

Changes in Social Network

A. Help provided to others.

1. Have there been any changes in how you are able to help others since you first started caring for ...? Could you please describe the changes?

2. Which if any of these changes have occurred since our last interview?

3. Do you expect any changes in the future? In what ways?

B. Help received from others.

1. Have there been any changes in how others have helped you since you first started caring for ...? Could you please describe the changes?

2. Which if any of these changes have occurred since our last

interview?

3. Do you expect any changes in the way others may help you in future? In what ways?

C. Changes in the Caregiving Relationship

1. Have there been changes in your relationship with ... since you first started caring for him/her? Could you please describe the changes?

2. Which of these changes if any have occurred since our last interview?

3. Do you expect any changes in this relationship in the future? In what ways?

Final Interview Guide

This is the last time I will be talking with you. I would like to review with you some of the things you have discussed with me previously.

Individualized Questions

Changes in Relationships

1. Are there any changes that have taken place in your relationships since our previous interviews? Please describe any changes in your relationships with others. Please describe you relationship with ...

Debriefing

As we conclude our discussions about you relationship with your family and friends while looking after ... I would be interested in hearing your thoughts about the experience of participating in this study. In what ways, if any, has your involvement in the study influenced your thinking about your relationships and the process of give and take in your relationships?

Would you be interested in receiving information about another research study about caregiving in the future?

APPENDIX B

Consent Form

Faculty of Nursing
University of Alberta

Research Study: Male caregivers' Perceptions of Social Support and Reciprocity

Researcher: Principal Investigator - Dr. Anne Neufeld
Associate Professor - Phone: 432-2699

The purpose of this study is to understand the social relationships of men who are caregivers. This study will provide no direct benefits to you but the results of the study will help nurses plan programs to assist other caregivers.

Part A:
You will be interviewed between 3 and 5 times during a 12-18 month period; each interview will last 1 to 1 1/2 hours. The interviews will be held at a time you choose in your home or at another location which you choose. The interview will be tape recorded. You will be asked to describe your relationship with the person you care for and to describe the help that you get from and give to others. You will also be asked to say what you consider to be important in life.

The information you give in the interview will be typed out. Your name will not appear on the typed interviews, or questionnaires, or in any reports of the study. During the study, only code numbers will be used to identify the interviews and questionnaires which will be stored in a locked file cabinet.

At the end of the study, the code list will be destroyed. The information you have given will be stored in a locked file cabinet for possible future analysis by Dr. Neufeld. Before the information is looked at again, the researcher will get permission from the appropriate ethical review committee.

Taking part in this study is voluntary. You may refuse to answer any question and you may withdraw from the study at any time by telling the interviewer.

If you have any questions while you are participating in the study, you can contact Dr. Neufeld. A copy of this consent will be given to you.

_____ _____
Research Assistant Signature of Subject

_____
Date

Part B:
In addition to the interviews, you may also agree to be part of a discussion group with other caregivers who have also been interviewed for this study. the group will be asked to comment on the findings from all the interviews in the study. This information will be presented in such a way that no one knows who said what. There will be one or two group discussions that will last one hour. The group discussions will be held as the end of the study. If you want to attend the discussion group please sign below. If you want to decide later, or if you do not want to attend the group discussion do not sign below.

Taking part in this study is voluntary. You may refuse to answer any question and you may withdraw from the study at any time by telling the interviewer.

If you have any questions while you are participating in the study you can contact Dr. Neufeld. A copy of this consent will be given to you.

_____ _____

Research Assistant Signature of Subject

_____

Date

If you wish to receive a typed summary of the information from the study please write you mailing address here:

_____

_____

_____

_____